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Cognitive Functioning and Psychological Wellbeing in Caregivers of People with Dementia

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Contents Page

Word Count Total: 14328

Systematic Review: 5758

Empirical Research Article: 4894

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Thesis Abstract

Background: It has been demonstrated informal caregivers of people with dementia (PWD) experience negative health outcomes. The current research explored caregivers' cognitive and emotional well-being, in the hope of advancing understanding of how caregivers can best be supported.

Objective: A systematic review was conducted to examine the relationship between caregiving for a PWD and cognitive functioning. An empirical study was conducted to examine the relationship between caregiving for a PWD and the experience of depressive symptoms. The empirical research aimed to understand how perceived suffering, intrusive thoughts and compassion contributed to caregivers depressive symptoms.

Methods: *Systematic review:* A search of electronic databases was conducted. The research papers were systematically reviewed using an adapted version of the Effective Public Health Practice Project quality assessment tool. *Empirical:* A cross-sectional, within-subjects design was used. Participants completed six standardised self-report questionnaires online. Mediation and moderated mediation analysis was conducted using the PROCESS macro for SPPSS.

Results: *Systematic review:* Fourteen papers were identified. There was evidence to suggest that caregivers of PWD had reduced complex attention when compared to controls. *Empirical:* Perceived suffering of a loved one and the occurrence of intrusive thoughts were significantly related to caregivers' depressive symptoms. Compassion was not found to moderate the relationship between perceived suffering and intrusive thoughts.

Conclusions: *Systematic review:* The findings suggested that caregivers found it more difficult to complete tasks involving complex attention when compared to non-

caregivers. There was not enough evidence to drawn conclusions about other areas of cognitive functioning. *Empirical:* Intrusive thoughts were found to be a potential pathway to depressive symptoms in caregivers' of PWD. Research findings support the development and implementation of interventions targeted at intrusive thoughts. Research findings did not support concerns related to trait compassion.

Lay Summary

Looking after a person with dementia can have negative consequences for the caregiver. The current study looked at how caregiving for a person with dementia impacts thinking ability and mood. The study was split into two parts.

Part 1 looked at a collection of past research articles. The past research articles looked at how caregiving impacts thinking ability. The strengths and weaknesses of the past research were reviewed. Following this, conclusions were made about caregivers thinking ability. It was concluded that caregivers found it more difficult that non-caregivers to perform different thinking tasks at the same time. There was not enough information to make conclusions about other areas of thinking.

In part 2 of the study, an original piece of research was completed. This meant that people volunteered to answer a number of questions. Caregivers of people with dementia were asked about their experience of low mood. Caregivers were also asked about things that may have caused their low mood. This included their opinions about their loved ones wellbeing, and their experience of unwanted thoughts. Caregivers were also asked about their compassion towards the self and others. The results found caregivers thoughts about their loved ones well-being was closely linked to their own low mood. Caregivers' experience of unwanted thoughts was also linked to low mood.

In summary, the current study found evidence to suggest that caregivers of people with dementia experience negative health outcomes. The study found caregivers experience impairment to one area of thinking ability. This was known as "complex attention". The study also found factors that contribute to low mood in caregivers of people with dementia. These included opinions about a loved ones well-being and the experience of unwanted thoughts.

Systematic Review

A Systematic Review: Cognitive Ability in Caregivers of People with Dementia

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This systematic review was written in the format required by the peer-reviewed journal *The Gerontologist*. Author guidelines are included in the appendices.

Abstract

Background and Objectives: Emerging research suggests that caregivers of people with dementia have reduced cognitive abilities when compared to controls. These findings could have serious implications for caregivers, care recipients and the care sector.

Research Design and Methods: This paper systematically reviewed the existing literature, with the aim of providing a greater understanding of the cognitive implications for caregivers of people with dementia. Fourteen studies met the inclusion criteria and were systematically reviewed using an adapted version of the Effective Public Health Practice Project quality assessment tool.

Results: There was strong evidence to suggest that caregivers of people with dementia had reduced complex attention when compared to controls. There was some limited support to suggest impairment in immediate and delayed recall, although this was not found across all studies. There was no support for impairment in verbal functions, language skills, concept formation, reasoning or executive functioning.

Discussion and Implications: The range of tests implemented to assess cognitive abilities was limited and thus restricted strong conclusions being drawn from the review. Research findings are discussed in relation to methodological weaknesses and implications for practice.

Keywords: caregiving; Alzheimer’s; memory; cognition

Informal caregiving (i.e. providing care in a non-professional capacity) for a person with dementia is recognised as an extremely stressful role (Brodaty & Donkin, 2009; Bruce et al., 2005; Gilhooly et al., 2016; González-Salvador, Arango, Lyketsos, & Barba, 1999). A large body of evidence suggests that caregivers of people with dementia (PWD) experience psychological and physical health implications, including higher risks of psychiatric morbidity and mortality (Capistrant, Moon, Berkman, & Glymour, 2012; Joling et al., 2010; Klein et al., 2016; Perkins et al., 2013). Although many caregivers describe their work as rewarding, research has linked caregivers' stress to lower mental and physical health status (Schulz, O'Brien, Bookwala, & Fleissner, 1995), elevated blood pressure (Fonareva & Oken, 2014; King, Oka, & Young, 1994), cardiovascular reactivity (Vitaliano, Russo, Bailey, Young, & McCann, 1993) and a higher number of chronic diseases (Pinquart & Sörensen, 2003). More recently, research has begun to explore the relationship between stress and cognitive abilities in caregivers of PWD.

Cognitive functioning refers to a range of mental processes relating to the acquisition, storage, manipulation, retrieval and expression of information (Lezak, Howieson, & Loring, 2012). Distinct cognitive processes are responsible for regulating specific behaviours and actions, allowing an individual's performance to be measured. Although the continued development of research and theory make it challenging to establish theoretically acceptable distinctions between different cognitive functions, Lezak, Howieson and Loring (2012) categorise cognitive functioning into seven broad constructs. These include 1) orientation and attention, 2) perception, 3) memory, 4) verbal functions and language skills, 5) construction and motor performance, 6) concept formation and reasoning, and 7) executive functions. A brief description of those constructs relevant to this review has been provided.

Attention is typically viewed as a sequence of automatic and controlled processes involved with the acquisition and sustaining of concentration (Lezak et al., 2012). Clinical assessment of attention typically involves an assessment of focused, sustained, divided and rapid alternating attention, as well as the ability to inhibit automatic or overlearned responses (Schoenberg & Scott, 2011). The most notable changes of attention which occur with ageing are declines in performance on complex attentional tasks such as selective or divided attention (Bigler, 2012).

Memory and learning abilities refer to information storage and retrieval. The assessment of memory usually includes both immediate and delayed recall, in addition to recall with recognition and cues (Lezak et al., 2012). Intact sensory, motor, arousal and attentional skills are a prerequisite for memories to encode, and internal cognitive aspects of functioning, such as reasoning and organisation, also play a significant role (Schoenberg & Scott, 2011). Memory capacities have been found to change considerably with ageing, and can also be affected by emotional functioning (Schoenberg & Scott, 2011).

Verbal functions and language skills are crucial for understanding and producing spoken and written language. Given its complexity, language abilities are typically assessed using batteries of tests investigating processes involving verbal comprehension, word definition, repetition, written language, naming, and written comprehension of words and sentences (Lezak et al., 2012). Language abilities are not only important for communicating with others, but also for structuring internal thoughts. Vocabulary, verbal reasoning, and verbal comprehension all remain stable into advanced age, whilst some confrontational naming tasks show a small decline with age (Bigler, 2012).

Tests of concept formation and reasoning differ from most other cognitive assessments because they focus on the quality or process of thinking more than the content of the response. Many tests have no explicit right or wrong answer, and instead provide information on how an individual thinks and conceptualises information (Lezak et al., 2012). Since many conceptual/reasoning functions are strongly linked to the prefrontal cortices, it is not unusual to find executive and conceptual/reasoning deficits occurring together (Goldberg, 2009). Despite this, many people who demonstrate good reasoning and thinking abilities suffer from significant executive impairment. As such, concept formation and reasoning can be considered as a distinct construct, found to have both a different clinical presentation and brain organisation (Lezak et al., 2012).

Finally, executive functions consist of those abilities that enable a person to establish new behaviour patterns and ways of thinking (Lezak et al., 2012). Skills involved in executive functioning are required in unfamiliar situations where established ways of behaving are no longer useful or appropriate (Burgess, 2010). Assessments of executive functions are probably the most technically and theoretically complex aspect of neuropsychological assessment and as such, executive tests should always be administered in the context of a wider neuropsychological assessment. Deficits in executive functioning can have a devastating impact upon an individual's effectiveness in everyday life and their relationships with others, leading to restlessness, impulsivity and dis-inhibition (Burgess, 2010).

Whilst the literature defines cognitive functioning in terms of broad constructs, cognitive abilities are often intrinsically intertwined and rarely occur in isolation (Lezak et al., 2012). Despite this, neuropsychological testing has been developed in an effort to examine cognitive constructs, and the cognitive abilities that underpin these processes. The current review largely makes reference to Lezak et al. (2012) "*Compendium of*

Tests and Assessment Techniques" to define cognitive abilities, whereby the authors categorise neuropsychological tests in accordance with the seven major constructs outlined previously. Consideration of additional literature was used to support and expand the outlined definitions.

Stress and Cognition

Stress has been found to have a negative impact on cognitive abilities (Aas et al., 2014; Pechtel & Pizzagalli, 2011). The stress hormone, cortisol, is known to supress functioning of the hippocampus, leading to atrophy of the hippocampus, which has been associated with memory impairments (Lupien, McEwen, Gunnar, & Heim, 2009). Research in the general population has illustrated that acute and short-term stressors, such as continuous loud noise, heat, and sleep deprivation, impair a wide range of cognitive abilities, including information processing, selective attention, procedural learning and working memory (Braunstein-Bercovitz, 2003; Braunstein-Bercovitz, Dimentman-Ashkenazi, & Lubow, 2001; Keinan, Friedland, Kahneman, & Roth, 1999; Mendl, 1999).

Impairments in cognitive abilities have also been related to naturally occurring forms of chronic stress. Research suggests caregivers of palliative patients had significant impairments in attentional abilities (Mackenzie, Smith, Hasher, Leach, & Behl, 2007) and individuals with post-traumatic stress disorder (PTSD) were found to have impairments in memory, auditory and visual attention, as well as executive functioning (Sandström, Rhodin, Lundberg, Olsson, & Nyberg, 2005). Consistent with these findings are structural neuroimaging studies that have repeatedly found associations between PTSD and loss of neural integrity in the hippocampus, amygdala, medial pre-frontal and anterior cingulate cortices (Miller & Sadeh, 2014).

While it is well documented that caregiving has negative effects on physical and psychological wellbeing, research examining the cognitive health of caregivers of PWD is in its early stages. This is surprising, given the volume of research that highlights stress in caregivers of PWD (Allen et al., 2017; Brodaty & Donkin, 2009; Cabote, Bramble, & McCann, 2015; Fonareva & Oken, 2014; Gilhooly et al., 2016), accompanied by evidence that illustrates the impact of stress on numerous cognitive pathways.

Caregiving and Cognition

It is widely accepted that caring for a PWD is an inherently stressful experience (Fonareva & Oken, 2014; Gilhooly et al., 2016). Despite this, research exploring cognition in caregivers of PWD is only recently emerging. This is surprising, given that caregivers are faced with important economic and legal decisions, as well as complex caregiving tasks, including understanding, remembering, and carrying out medical responsibilities (Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008; Fjell et al., 2014; Nordberg, von Strauss, Kåreholt, Johansson, & Wimo, 2005; Savla, Roberto, Blieszner, Cox, & Gwazdauskas, 2011). Estimates suggest that around 850,000 people currently live with dementia in the UK (Prince et al., 2014), and that two-thirds of these individuals are cared for at home by informal caregivers (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Given these figures are expected to rise, clarification of the impact of caregiving on cognitive abilities is imperative, particularly because caregivers of PWD tend to be older adults who may be at increased risk for cognitive changes associated with normal ageing (Harada, Natelson Love, & Triebel, 2013).

Impairments to cognitive abilities could have implications for treatment outcomes and opportunities as well as informing future health strategies. A recent

article addressed ways in which cognitive abilities may be ameliorated, protected or mitigated within the healthcare setting; it stipulates, however, that an awareness of such deficits is essential to provide appropriate care (Vance, Larsen, Eagerton, & Wright, 2011).

To date, a small number of studies have illustrated that caregivers of PWD have reduced cognitive abilities when compared to controls (de Vugt et al., 2006; Oken, Fonareva, & Wahbeh, 2011). Caregivers of PWD have been found to perform worse than matched controls on measures of processing, attention and concentration (Caswell et al., 2003; de Vugt et al., 2006; Oken et al., 2011). Furthermore, longitudinal studies have shown that caregivers of PWD had reduced scores in vocabulary and working memory (Vitaliano et al., 2009) when compared to controls. Current research, though concerning, reports conflicting results, with some studies reporting no observed differences in caregivers of PWD when compared to controls (O'Sullivan et al., 2018).

Certainty regarding caregivers' cognition has serious implications for practice and therefore warrants clarification. If caregivers are at increased risk of impaired cognitive ability, healthcare services would benefit from developing systems that enable this vulnerable population to be identified early on, allowing the provision of support from an early stage.

As such, this review aims to provide a greater understanding of the cognitive implications for caregivers of PWD, compared to controls, afforded by the collation of existing research evidence.

Research Design and Methods

Search Strategy

An initial scope of the literature was conducted in December 2018 to identify, develop and refine the review question. A detailed review of the literature was undertaken on the 18th February 2019, ensuring previous reviews of a similar nature had not been submitted to the Cochrane Database of Systematic Reviews (CDSR) or the International Prospective Register of Systematic Reviews (PROSPERO). In this absence, a research protocol was devised and submitted to PROSPERO. See Appendix A.

The search strategy to identify relevant literature for the review was conducted and included the following databases: PsyINFO, EMBASE, Medline, Scopus and CINAHL. The OVID interface was used to amalgamate the search engines for PsyINFO, Embase and Medline databases. Unpublished research and grey literature was searched for using OpenGrey and ProQuest Dissertation and Thesis Global. In addition, bibliographies and reference lists of retrieved articles were closely examined and contact was made with experts in the field to ensure that unpublished sources known to experts were not missed.

Search Terms

To ensure the appropriateness of key search terms, research papers and past reviews were consulted (Allen et al., 2017; Fonareva & Oken, 2014). Synonyms, spelling variations, abbreviations, truncation and Boolean operators were used to ensure maximum return and reduce irrelevant hits. Keywords for search terms were related to caregiving (e.g. ‘carer’, ‘care giver’, ‘caregiv*’), dementia (e.g. ‘dementia’, ‘alzheimer*’, ‘neurodegen*’) and cognitive functioning (e.g. ‘cognit*’, ‘neuropsych*’, ‘neurocognit*’). See Table 1 for an example of the search strategy using the CINHAL

search engine. Resource constraints meant that the search strategy was limited to studies that were published in English between the years 2000 and 2019.

Table 1

Search Strategy using the CINHAL Search Engine

1. Carer OR caregiv* OR care giver*
2. Dementia OR alzheimer* OR neurodegen*
3. Cognit* or Neuropsych* or Neurocognit* or memor*
4. 1 AND 2 AND 3
5. Limit to English language
6. Human studies
7. 2000-2019
8. 4 AND 5 AND 6 AND 7

Search Limits

Search limits were applied according to the individual databases. Parameters included English language and peer-reviewed articles. The articles were initially scanned to ensure relevance of topic and duplicates were removed. The articles were imported into the reference management software Mendeley, where duplicates were removed.

The relevance of each study recovered was assessed against the inclusion and exclusion criteria (see Table 2 and Table 3) by the primary author. Time constraints prevented the search output to be independently verified by a second reviewer. The title and abstracts of each article were reviewed, and the full articles were inspected when there was ambiguity regarding the study's relevance.

Table 2

Study Inclusion Criteria

Population(s)	Informal caregivers of people with dementia
Assessment	Measure of cognitive function
Comparators	Caregivers of people with dementia compared to controls
Outcomes	Objective measures such as: Global measure of cognitive functioning OR At least one measure of cognitive ability that falls within the constructs outlined below: • Orientation and attention • Perception • Memory • Verbal functions • Language skills • Construction and motor performance • Concept formation and reasoning • Executive functioning
Study design	Observational

Table 3

Study Exclusion Criteria

Studies examining cognitive functioning using brain imaging activity
Publications before 2000
Grey literature/ Not peer-reviewed literature
Studies published in a language other than English
Qualitative research
Book chapters
Case studies
Responses/ letters of reply

Data Extraction and Quality Assessment

Data were extracted from each paper by the first author according to a structured pro forma, covering key study characteristics. The quality of the included studies was assessed according to an adapted version of the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool (QAT) for Quantitative Studies (Effective Public Health Practice Project, 2009) (see Appendix B). As the EPHPP has primarily been designed for the appraisal of interventions, the tool was adapted to meet the requirements of apprising observational studies. Consultation of the "STROBE Statement-Checklist of items that should be included in reports of cross sectional studies" was used to inform the adapted version of the EPHPP as well as the "Appraisal Tool for Cross-Sectional Studies" (AXIS tool; Downes, Brennan, Williams, & Dean, 2016).

The adapted EPHPP QAT considered six types of bias: selection bias; study design; cofounders; blinding; data collection; withdrawals and drop-outs. For each criterion, studies were assigned one of three outcome ratings: strong, moderate or weak. The component ratings were reviewed accordingly and a global rating for the paper was given.

Results

Figure 1 shows the search process and the number of included and excluded studies.

Summary

Fourteen papers were included in the review; their characteristics and results are summarised in Table 4. Research by Vitaliano, Echeverria, Shelkey, Zhang and Scanlan (2007) was excluded from the review as it utilised the same sample, outcome measures and partial analysis as results compiled in Vitaliano et al. (2009). The latter paper expanded on the original study by including additional analyses. Research published by O'Sullivan, Pertl, Brennan and Robertson (2016) was also excluded from the review on the same basis.

Figure 1

Flow Diagram of Search Process

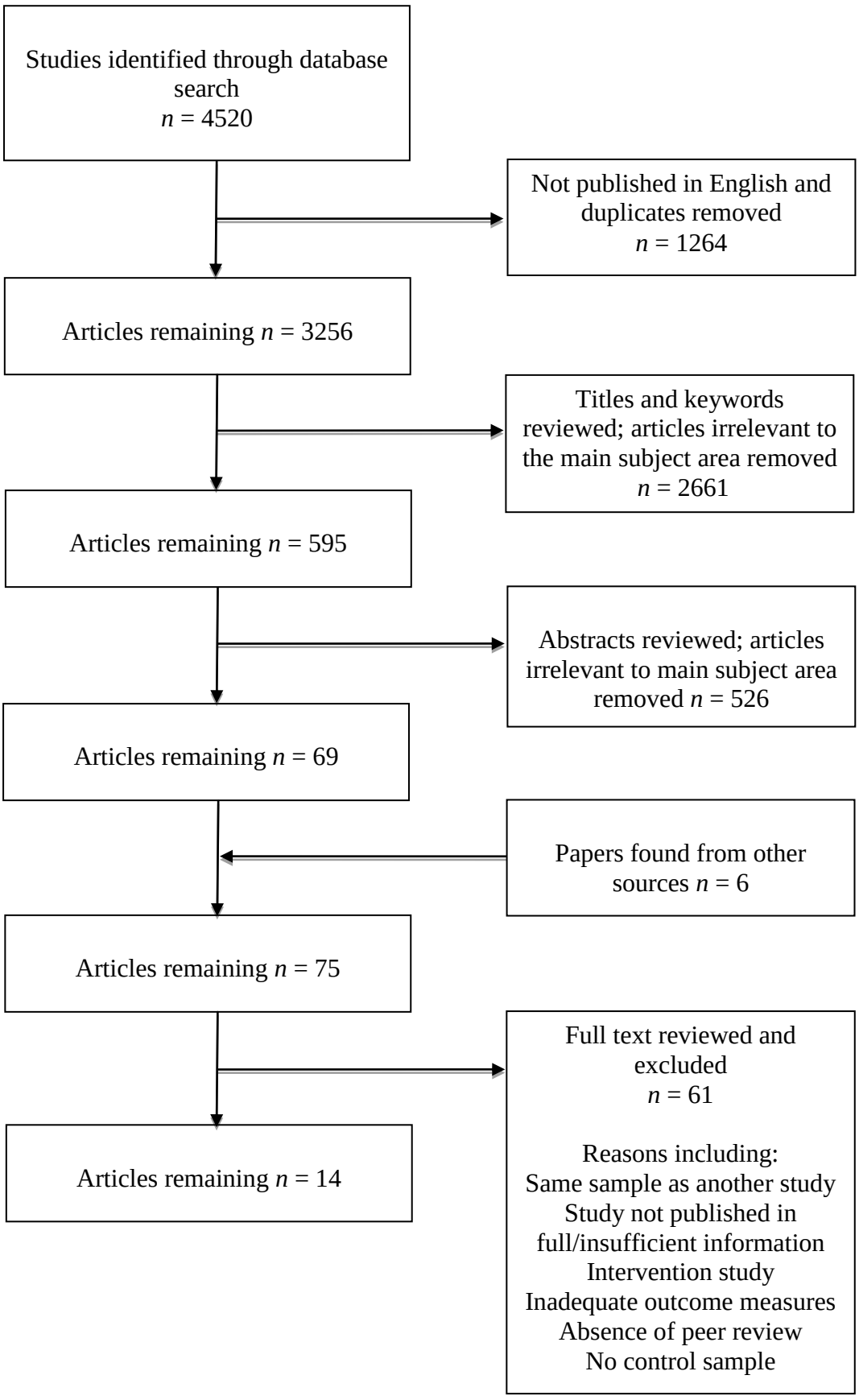

Table 4

Summary of Studies Measuring Cognitive Abilities in Caregivers of People with Dementia

Authors	Study design	Sample *n*; Mean age; % female	Relation to care recipient	Cognitive measures	Group differences	Related or modifying variables
Caswell et al., 2003	CS	**DCG:** *n* = 44; 74 y.o.; 53% **CTL:** *n* = 66; 71 y.o.; 68%	100% PWD spouse	WAIS-R; DST	DCGs scored worse for complex attention and processing speed, *d* = .61.	DST score was predicted by DCG, $R^2 = 0.03$, $p < 0.035$. DST scores were also affected by age and education.
Vitaliano et al., 2005	Long. F/u: 2yrs	**DCG:** n = 96; 72 y.o.; 60% **CTL:** n = 95; 71 y.o.; 62%	100% PWD spouse	SILS - Vocabulary and abstraction subtest	Groups were similar at baseline. At follow up DCGs, but not CTLs, had a 1-point decline on the vocabulary test, $p < .05$.	Hostile attribution and metabolic risk mediated DCG cognitive decline.
de Vugt et al., 2006	Long. F/u: 1yr	**DCG:** *n* = 54; 68 y.o.; 59% **CTL:** *n* = 108; 68 y.o.; 59%	100% PWD spouse	MMSE; AVLT - delayed recall; DSC; Stroop	DCG performed worse on MMSE, *d* = -.42, delayed recall, *d* = -.49, and LDCT, *d* = -.77, but groups were similar on Stroop, *d* = .33.	Verbal memory task score was related to DCG subjective competence and hyperactivity in the PWD.
Vitaliano et al., 2009	Long. F/u: 2yrs	**DCG:** n = 122; 72 y.o.;62% **CTL:** *n* = 117; 70 y.o.; 64%	100% PWD spouse	MMSE; DST	At 2yrs f/u DCGs had lower DST score, *d* = .38. DCGs experienced a more rapid decline in cognitive performance (at least 4.5 times faster) than CTLs.	Depression score at baseline predicted DST decline in DCG and CTL.
Oken et al., 2011	CS	**DCG:** n= 31; 65 y.o.; 81% **CTL:** *n* = 25; 67	Not reported	mTICS; ANT; Stroop; CERAD - Word recall	DGC performed worse than CTL on attention *p* = .006; executive function *p*	Quality of sleep was related to DCG cognitive performance.

		y.o.; 88%			= .03. Both groups were similar on the word memory test p = .51.	
Palma et al., 2011	CS	**DCG:** n = 14; age range: 66–74; 50% **CTL young:** n = 19; age range: 35–49; 80% **CTL old:** n = 24, age range 61–82; 83%	Not reported	MMSE; Memory task (delayed recall of emotionally arousing or neutral story)	Unlike older CTLs, DCGs did not benefit from emotionally arousing material, p > .05. DCG had worse scores overall all than CTL old, p = 0.011.	Night time cortisol levels, which were higher in DCG, predicted memory performance.
Corrêa et al., 2015	CS	**DCG:** n= 17; 64 y.o.; 76% **CTL:** n= 18; 58 y.o.; 77%	Not reported	MMSE; DSPT; TMT; LMT	DCG performed worse than CTL on: forward DSPT p > .00, backward DSPT p >.001 and on TMT B: p = .012.	Night-time cortisol was negatively correlated with all cognitive tasks in which DCG showed impaired performance.
Pertl et al., 2015	PB	**DCG:** n = 179; 73 y.o.; 55% **Matched CTL:** n = 179, 72 y.o.; 55%	100% PWD spouse	mTICS; WJ-III - number series task; WAIS-R - word definition	No difference between groups was reported, p < .05.	Higher levels of depression predicted poorer cognitive performance across groups.
Corrêa et al., 2016	CS	**Old DCG:** n = 18; 74 y.o. 83% **Young DCG:** n = 17; 49 y.o.; 88% **Old CTL:** n = 18; 68 y.o.; 72% **Young CTL:** n = 17; 46 y.o.; 82%	Not reported	MMSE; DST; TMT; Stroop; LMT	Young and old DCG had lower scores than age-matched controls on forward and backward DSPT; TMT B; Stroop and LMT (p < .05).	Young DCG scored significantly worse than old CTL on forward and backward DSPT and in LMT I and II p < 0.05).
(Lathan et al., 2016)	CS	**DCG:** n = 527; 60 y.o.; 88%	51% family members	DSC; MS; TMT	Caregivers scored significantly worse than	Stress, sleep, perceived support, self-rated health,

		CTL: *n*= 527*;* matched on age, gender, race, education	38% spouse		controls on DSC ($p <$ .001) and MS ($p <$ .001). No difference emerged on TMT.	years of caregiving, race and gender were significant predictors of cognitive performance.
Dassel, Carr, Vitaliano, & Pruchno, 2017	PB Long. F/u: up to 8yrs	**DCG**: *n* = 192; 76 y.o.; 71% **CTL:** *n* =1063; 72 y.o.; 74%	100% spouse	mTICS	DCG had significantly greater cognitive decline ($p < .01$) compared to CTL.	Location of death and age at death predicted DCG changes in cognitive health.
Vitaliano, Ustundag, & Borson, 2017	Long F/u: 2yrs	**DCG:** *n* = 122; 72 y.o.; 62% **CTL:** *n*= 117; 70 y.o.; 64%	100% spouse	MMSE; TMT; DST; SILS	DCG scored worse on DST across 3 time points ($p >$.001) and on TMT B at time points 1 and 2 (p>.05).	There was no difference on TMT B between groups at time point 3. Depression mediated group differences on TMT and DST.
(Mallya & Fiocco, 2018)	CS	**DCG**: *n* = 57; 66 y.o.; 81% **CTL**: *n* = 97; 69 y.o.; 72%	Not reported	MMSE; TMT; COWAT; CVLT-II	DCG made more errors on a cognitive flexibility test ($p = .02$), generated fewer words on phonemic ($p < .01$) and semantic fluency tests ($p < .001$) and learned fewer words ($p < .01$).	DCG reported experiencing more perceived stress ($p <$ .001) and lower quality of life ($p < .001$).
O'Sullivan et al., 2018	PB	**DCG:** *n* = 179, 67 y.o.; 70% **CTL group 1**: *n* = 179; 67 y.o.; 71% **DCG**: *n* = 155, 67 y.o.; 66% **CTL group 2**: control: *n* = 155; 66 y.o.; 67%	100% spouse	MoCA; CRT; TMT; Category Fluency; LMT; FCSRT	DCG and CTL were comparable in most cognitive domains. DCG had significantly better processing speed ($p <$.05), reaction time (p<.05) and free recall (p<.001).	DCG had higher levels of stress and depression.

Note. ANT= Attention Network Task, AVLT = Auditory Verbal Learning, CERAD = Consortium to Establish a Registry for Alzheimer's Disease, COWAT = Controlled Oral Word Association, CRT = Choice Reaction Time, CS = cross sectional, CTL = control, CVLT-II California Verbal Learning Test- Second Edition, DCG = dementia caregiver, DSC = Digit Symbol Coding, DSPT = Digit Span Test, DST = Digit Symbol Test, FCSRT = Free and Cued Selective Reminding Test, F/u = follow up, LMT= Logical Memory Test, Long. = longitudinal, MMSE = Mini-Mental State Examination, MoCA = Montreal Cognitive Assessment, MS = Memory Span, mTICS = modified Telephone Interview for Cognitive Status, PB = population based, PWD = person with dementia, SILS = Shipley Institute of Living Scale, Stroop = Stroop Color-Word Test, TMT = Trail Making Tests, WAIS-R = Wechsler Adult Intelligence Scale-Revised, WJ-III =Woodcock-Johnson III, yr/s = year/s, y.o. = years old.

Study Characteristics

The 14 studies described data from 4901 participants, including 2077 caregivers of PWD and 2825 controls. The mean sample size was 327. The studies included in the review were published between 2003 and 2018. In total, 29 tests assessing cognitive ability were implemented; see Appendix C for details.

Since many neuropsychological measures can be said to assess a number of cognitive constructs and there is often ambiguity about which cognitive ability is placed upon individuals in any given test. Lezak et al.'s (2012) categorisation of neuropsychological assessments has been broadly followed when tabulating and discussing the measures used in the reviewed studies.

Measures of Cognitive Functioning

Global Measures of Cognitive Ability

To ensure participants were within the expected limits of mental functioning, prior to carrying out cognitive testing nine studies reported using a screening tool. Six studies implemented the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) (Corrêa et al., 2015; Corrêa et al., 2016a; de Vugt et al., 2006; Mallya & Fiocco, 2018; Palma et al., 2011) and one study used the modified Telephone Interview for Cognitive Status (mTICS; Brandt, Spencer, & Folstein, 1988) (Oken et al., 2011). One study reported screening for cognitive ability, conceptualising low educational attainment as a screening measure (O'Sullivan et al., 2018). Two studies implemented the MMSE to confirm the diagnosis of dementia in the care recipient (Vitaliano et al., 2017, 2009).

Three studies implemented global measures to assess cognitive ability in caregivers compared to controls. The mTICS (Brandt et al., 1988) was used in two

studies (Dassel et al., 2017; Pertl et al., 2015). The Montreal Cognitive Assessment (MOCA; Nasreddine et al., 2005), a widely-used rapid screening instrument for mild cognitive dysfunction, was used in one study (O'Sullivan et al., 2018). Significant differences were not observed between DCG and controls, see Table 5 for details.

Attention

Test of attentional abilities were implemented in 11 studies, using ten different tests. Cognitive abilities were classified into attentional capacity, complex attention, processing speed and working memory in accordance with (Lezak et al., 2012).

Attentional capacity was assessed in three studies, all of which found caregivers of PWD performed significantly worse than controls. The Digit Span Forwards sub tests from the Wechsler Adult Intelligence Scale III (WAIS-III; Kaufman & Lichtenberger, 1999) was implemented in two studies. One study implemented the Forward Memory Span subtests from the Corsi Block Tapping Test (CBTT; Milner, 1971). Complex attention was assessed using the Digit Symbol Coding (DSC) subtest from the Wechsler Adult Intelligence Scale – revised (WAIS-R; Wechsler, 1981) in five studies (Caswell et al., 2003; de Vugt et al., 2006; Lathan et al., 2016; Vitaliano et al., 2017, 2009), whereby caregivers of PWD people consistently performed worse than controls.

Processing speed was assessed in six studies. The Attention Network Test (Fan, McCandliss, Sommer, Raz, & Posner, 2002) was implemented in one study (Oken et al., 2011). Caregivers of PWD were found to score significantly worse than the control group. A choice reaction test was used in one study involving two control groups: population based and self-selecting controls (O'Sullivan et al., 2018). Interestingly, caregivers of PWD scored significantly better than both control groups, though the effect sizes were small. The Colour Trails Test I (D'Elia, Satz, Uchiyama, & White,

1996) was used in one study (O'Sullivan et al., 2018). Again, caregivers of PWD were found to perform better than population-based controls, however no significant difference was found between caregivers of PWD and self-selecting controls. The Trail Making Test A (Strauss, Sherman, & Spreen, 2006) was used in four studies. In three of the studies no significant group differences were found. In Corrêa et al. (2016), older caregivers of PWD were found to perform worse than age-matched controls (mean age 68), however no difference was observed between young caregivers of PWD and age-matched controls (mean age 46).

Finally, working memory was assessed in four studies. Two studies used the Digit Span Backwards sub tests from the WAIS-III (Kaufman & Lichtenberger, 1999), finding caregivers of PWD performed significantly worse than controls. The Reverse Memory Span subtests derived from the CBTT (Milner, 1971) was used in one study, finding that caregivers of PWD performed significantly worse than controls. The Letter Number Sequencing subtest of the Wechsler Memory Scale- III (WMS III; Kreutzer, DeLuca, & Caplan, 2011b) was used in one study, however no significant difference was found between groups (O'Sullivan et al., 2018). See Table 5 for details.

Memory and Learning

Memory was investigated in seven studies using seven verbal memory measures. Memory abilities were categorised into delayed and immediate recall. For delayed recall, the Auditory Verbal Learning Test (AVLT; Brand & Jolles, 1985) was used in one study. Findings reported caregivers of PWD performed significantly worse than controls (de Vugt et al., 2006). The Long Delay Free Recall subtest from The California Verbal Learning Test – Second Edition (CVLT-II; Delis, Kramer, Kaplan, & Ober, 2000) found no significant differences between caregivers of PWD and controls (Mallya

& Fiocco, 2018). The Free and Cued Selective Reminding Test (FCSRT; Grober, Buschke, Crystal, Bang, & Dresner, 1988) was used in one study, reporting that caregivers of PWD performed better than controls (O'Sullivan et al., 2018). The Logical Memory Test II (LTMT-II) subtest from the Wechsler memory scale III (WMS-III; Wechsler, 1997) was used in three studies. Caregivers of PWD were found to perform worse than controls in two of the three studies. Finally, a story paradigm was implemented in one study (Palma et al., 2011), which reported no significant difference between groups. The Word List Recall subtest from the Consortium to Establish a Registry for Alzheimer's Disease (CEDEAR) (Moms et al., 1989) was used in one study (Oken et al., 2011), and found no significant difference between groups.

For immediate memory, the Logical Memory Test I subtest from the WMS-III (LTMT-I; Wechsler, 1997) was used in three studies (Corrêa et al., 2015; Corrêa et al., 2016; O'Sullivan et al., 2018). Caregivers of PWD were found to perform worse than controls in two of the three studies. The Total Words score from the CVLT-II was used in one study and found no difference between groups (Mallya & Fiocco, 2018). See Table 5 for details.

Verbal Functions and Language Skills

Verbal functions were assessed in two studies using vocabulary abilities. Vitaliano et al. (2005) used the vocabulary subtest from the Shipley Institute of Living Scale (SILS; Zachary, 1986) and reported that caregivers' vocabulary declined over a two-year period, whilst controls did not. Pertl et al. (2015) reported no difference between caregivers of PWD and controls using a test based on the word definition subtest of the WAIS-R (Wechsler, 1981). See Table 5 for details.

Concept Formation and Reasoning

Concept formation and reasoning was assessed in two studies. The Abstraction subtest of the SILS (Zachary, 1986) was used in one study, reporting no difference between caregivers of PWD and controls (Vitaliano et al., 2005). A Number Series Task, based on the Woodcock-Johnson III test battery (WJ-III; Woodcock, McGrew, & Mather, 2005; Mather & Wendling, 2010) was used in one study (Pertl et al., 2015) and similarly found no difference between groups. See Table 5 for details.

Executive Functioning

Executive functioning was assessed in nine studies using six measures. Results were considered in terms of verbal fluency and set shifting. The Category Fluency Task (Lezak et al., 2012) and the Controlled Oral Word Association Tasks (COWAT; Benton, 1989) were implemented to assess verbal fluency in two studies (Mallya & Fiocco, 2018; O'Sullivan et al., 2018). Caregivers of PWD were found to score worse than controls on both subtests of the COWAT.

Set shifting was assessed in nine studies using three tests. No difference was found between groups in the Colour Trails Test II (CTT-II; D'Elia et al., 1996) and caregivers of PWD were found to perform significantly worse than controls in all studies using the Stroop Color and Word Test (Houx, Jolles, & Vreeling, 1993). The Trail Making B test was implemented in five studies and showed mixed results. Caregivers of PWD performed worse than controls in two studies (Corrêa et al., 2016; Corrêa et al., 2015), however no significant difference was found in a further three studies (Lathan et al., 2016; Mallya & Fiocco, 2018; Vitaliano et al., 2017). See Table 5 for details.

Summary of Neuropsychological Findings

No difference between groups was observed using global measures of cognitive functioning. Despite this, differences between groups were observed using tests which measured specific cognitive constructs.

Significant differences in cognitive abilities were found between caregivers of PWD and controls in all but one study (Pertl et al., 2015). Where differences in cognition were observed, caregivers of PWD consistently performed worse than controls, excluding one study where caregivers of PWD were found to have significantly better processing speed, divided attention and delayed recall (O'Sullivan et al., 2018).

Cognitive testing disproportionately assessed attention when compared to other cognitive constructs. Assessment of executive functioning was explored in some depth, though was limited to set shifting and problem solving. Likewise, assessment of memory was limited to immediate and delayed recall. Finally, assessment of global cognition, verbal functions and language skills, and concept formation was extremely limited.

Table 5

Cognition in Caregivers of People with Dementia Compared to Controls

Cognitive construct	**Cognitive ability measured**	**Test**	**Study/author**	**DCG vs CTL**	***d***
General cognition	Global cognition	Modified Telephone Interview for Cognitive Status	Dassel et al., 2017 Pertl et al., 2015	- -	0.11 0
		Montreal Cognitive Assessment	O'Sullivan et al., 2018 O'Sullivan et al., 2018	- -	0.15[a] 0.09[b]
Attention	Attentional capacity	Digit Span Forward (WAIS III)	Corrêa et al., 2015 Corrêa et al., 2016 Corrêa et al., 2016	↓ ↓ ↓	0.34 10.20[c] 8.55[d]
		Forward Memory Span (CBTT)	Lathan et al., 2016	↓	0.30
	Complex attention	Digit Symbol Coding	Lathan et al., 2016 Caswell et al., 2003 Vitaliano et al., 2009 Vitaliano et al., 2017 de Vugt et al., 2006	↓ ↓ ↓ ↓ ↓	0.38 0.61 0.38 0.39 -0.77
	Reaction time/Processing speed	Attentional Network Test	Oken et al., 2011	↓	0.6
		Choice Reaction Time Test	O'Sullivan et al., 2018 O'Sullivan et al., 2018	↑ ↑	0.28[a] 0.24[b]
		Colour Trails Test I	O'Sullivan et al., 2018 O'Sullivan et al., 2018	↑ -	0.22[a] 0.1[b]
		Trail Making A	Corrêa et al., 2015 Corrêa et al., 2016 Corrêa et al., 2016 Lathan et al., 2016 Mallya & Fiocco, 2018	- ↓ - - -	0.59 6.55[c] 2.11[d] 0.08 0.24

			Mallya & Fiocco, 2018		
	Working memory	Digit Span Backwards (WAIS III)	Corrêa et al., 2015 Corrêa et al., 2016	↓↓ ↓↓	8.46 13.4
		Letter Number Sequencing (WMS III)	O'Sullivan et al., 2018	-	0.11[b]
		Reverse Memory Span (CBTT)	Lathan et al., 2016	↓↓	0.25
Memory and learning	Verbal memory: Delayed recall	Auditory Verbal Learning Test	de Vugt et al., 2006	↓↓	-0.49
		Long Delay Free Recall (CVLT-II)	Mallya & Fiocco, 2018	-	0.06
		Free and Cued Selective Reminding Test	O'Sullivan et al., 2018	↑↑	0.33[b]
		Logical Memory Test II	Corrêa et al., 2015 Corrêa et al., 2016 Corrêa et al., 2016 O'Sullivan et al., 2018	- ↓↓ ↓↓ ↓↓	3.9 7.33[c] 9.87[d] 0.1[b]
		Story Paradigm	Palma, 2011	-	u/a
		Word List Recall Test (CEDRAD)	Oken et al., 2011	-	-0.16
	Verbal memory: Immediate recall	Logical Memory Test I	Corrêa et al., 2015 Corrêa et al., 2016 Corrêa et al., 2016 O'Sullivan et al., 2018	- ↓↓ ↓↓ ↓↓	3.4 9.4[c] 8.7[d] 0.17[b]
		Total Words (CVLT-II)	Mallya & Fiocco, 2018	↓↓	0.26
Verbal functions and language skills	Vocabulary	Vocabulary Subtest (SILS)	Vitaliano et al., 2005	↓↓	0.64
		Word Definition (WAIS-R)	Pertl et al., 2015	-	0.17
Concept formation and reasoning	Concept formation	Abstraction (SILS)	Vitaliano et al., 2005	-	0.03
	Reasoning	Number Series Task (WJ III)	Pertl et al., 2015	-	0.05

Executive functioning	Verbal fluency	Category Fluency Task	O'Sullivan et al., 2018	-	0.04[b]
		Controlled Oral Word Association Task - Animals	Mallya & Fiocco, 2018	↓	0.47
		Controlled Oral Word Association Task – F A S	Mallya & Fiocco, 2018	↓	0.4
	Set shifting	Colour Trails Test II	O'Sullivan et al., 2018 O'Sullivan et al., 2018 Pertl et al., 2017	- -	0.03[a] 0.03[b]
		Stroop Colour Word Test	Corrêa et al., 2015 Corrêa et al., 2016 de Vugt et al., 2006 Oken et al., 2011	↓ ↓ - ↓	3.78[c] 8.33[d] 0.33 0.38
		Trail Making B	Corrêa et al., 2015 Corrêa et al., 2016 Corrêa et al., 2016 Lathan et al., 2016 Mallya & Fiocco, 2018 Vitaliano et al., 2017	↓ ↓ ↓ - - -	4.98 4.11[c] 6.61[d] 0.12 0.13 0.1

↓ Indicates significantly worse performance than controls
↑ Indicates significantly better performance than controls
– Indicates no significant differences compared to controls

Data analysis differentiated, using specific control groups in the indicated studies. [a] Comparison using population based controls; [b] Comparison using self-selecting controls; [c] Comparison using older caregiver controls; [d] Comparison using young caregiver controls

Assessment of Methodological Quality

Table 6 contains study ratings on the six quality criteria selected. The rating system provides an indication of the methodological strengths of the studies reviewed relative to each other. Research findings should be considered in line with quality assessment. Only six studies were considered to be of moderate quality, calling into question findings from the remaining studies. Studies that were considered to be of higher quality tended to report fewer significant results.

Table 6

Quality Assessment of Studies

Name of study	Selection bias	Study design	Cofounders	Blinding	Data collection	Withdrawals & dropouts	Overall rating
Caswell et al., 2003	+	+	+++	+	+	+	+
Vitaliano et al., 2005	+	++	+++	++	++	+++	++
de Vugt et al., 2006	+	++	+++	++	++	+++	++
Vitaliano et al., 2009	+	++	+++	++	+	+++	+
Oken et al., 2011	+	+	++	++	+++	+	+
Palma, 2011	+	+	+	+	++	+	+
Corrêa et al., 2015	+	+	++	++	++	+	+
Pertl et al., 2015	+	++	+++	++	++	+++	++
Corrêa et al., 2016	+	+	++	++	++	+	+
Lathan et al., 2016	+	++	+	++	+	++	+
Dassel et al., 2017	++	++	+++	++	+	++	++
Vitaliano et al., 2017	+	++	+++	++	++	+++	++
Mallya & Fiocco, 2018	+	+	+++	++	++	+	+
O'Sullivan et al., 2018	++	++	++	++	++	+++	++

Abbreviations: +++ = strong, ++ = moderate, ++ = weak.

Quality Assessment Findings

Three of the studies used population-based data (Dassel et al., 2017; O'Sullivan et al., 2018; Pertl et al., 2015). The remaining studies used convenience sampling whereby caregivers tended to be recruited through dementia support services, and control groups tended to be self-selecting research volunteers, recruited through media, active

retirement clubs and social groups. As such, it is possible that findings reflect the cognitive advantages of being a socially active older adult, rather than reduced cognitive ability as a result of stressful caregiving.

Only two studies (O'Sullivan et al., 2018; Pertl et al., 2015) reported on the number of participants that agreed to participate in the study. No study reported implementing random sampling or demonstrated participants were similar to those who did not opt to participate.

None of the studies reported conducting a power calculation prior to beginning the study. Three studies reported having less than 20 participants in each group (Palma et al., 2011; Correa et al. 2015; Correa et al., 2016). The majority of studies carefully considered co-founders by assessing for significant medical conditions, psychiatric conditions and medication use that had the potential to affect cognitive performance. One study excluded participants if cognitive testing had been completed in the past year (Mallya & Fiocco, 2018), due to potential learning effects. In one study there was a significant difference between groups with regards to gender, which was not adjusted for (Palma et al., 2011). In another, participants were matched on age, gender and education, however no additional co-founding factors were considered (Lathan et al., 2016).

In two of the studies, the administrators of cognitive testing were aware of the status of the participants (Dassel et al., 2017; Oken et al., 2011). In the remaining studies it was difficult to tell whether or not the administrators were blind to the participants' status. The same administrator completed cognitive testing across participants in three studies (Caswell et al., 2003; Lathan et al., 2016; Oken et al., 2011), however in the remaining studies this was unclear. Only three studies clearly state that the administrator was appropriately trained to deliver cognitive testing

(Caswell et al., 2003; Oken et al., 2011; Vitaliano et al., 2005). In seven studies it was explicit that cognitive testing was completed in line with standardised procedures (Caswell et al., 2003; Corrêa et al., 2015; Corrêa et al., 2016; O'Sullivan et al., 2016; Oken et al., 2011; Pertl et al., 2015; Vitaliano et al., 2017), however this was not specified in the remaining studies, with at least one study completing testing in the home environment (Dassel et al., 2017).

Only two studies reported on the reliability and validity of the measures used (Pertl et al., 2015; Vitaliano et al., 2009), therefore these properties had to be investigated further. The majority of measures were described with psychometric properties in Lezak et al. (2012), where a detailed description of neuropsychological assessments were described as valid and reliable.

Generally, the measures implemented were well established with good psychometric properties. Whilst some studies measured the same component, no one test was consistently implemented across studies. There was a notable variance in the number of cognitive constructs assessed in each study. O'Sullivan et al. (2018) measured cognitive functioning across five constructs, whilst two studies only measured one cognitive construct (Caswell et al., 2003; Vitaliano et al., 2009). In general, studies were poor at providing justification as to why a specific cognitive construct or process was chosen for assessment.

Discussion and Implications

This review examined cognition in caregivers of PWD. Only fourteen studies were included in the review, highlighting the dearth of research in this area. The results indicated some meaningful and significant findings, though should be interpreted with

caution due to methodological weaknesses.

There was no difference observed between caregivers of PWD and controls in studies using the MMSE as a global measure of cognitive functioning. Since the MMSE has been criticised for being insufficient in detecting subtle variations in performance scores or changes in cognitive profile (Antony, Weaver, Rueffer, Guthrie, & Evans, 2017), these findings are not surprising.

Only seven studies reported using a validated tool to ensure participants were within the expected limits on cognitive functioning prior to participating in the study (Corrêa et al., 2015; Corrêa et al., 2016a; de Vugt et al., 2006; Mallya & Fiocco, 2018; Palma et al., 2011; Oken et al., 2011.) As such, it is difficult to tell whether participants in the remaining studies had an underlying impairment that could have cofounded the result (such as an unidentified learning disability, head injury or an emerging dementia), and therefore the results should be interpreted with caution.

Differences in cognitive ability between caregivers of PWD and controls were most evident in attention. There was strong evidence to suggest that caregivers of PWD had reduced complex attention, as assessed consistently across five moderately rated studies, using DSC. Despite this, it is important to note that depressed mood is more common in caregivers of PWD (Gallagher-Thompson et al., 2006), and depressive symptoms have been associated with poor scores in DSC (Cerhan et al., 1998), as well as longitudinal decreases in DSC (Yaffe et al., 1999). Consequently, additional evidence to strengthen these findings using a range of neuropsychological tests is warranted.

There was some evidence to suggest that caregivers of PWD experience deficits in immediate and delayed recall; findings should be interpreted tentatively, however, as a number of studies were at high risk of bias. In two high risk studies (Corrêa et al., 2015; Corrêa et al., 2016) caregivers of PWD were on average six years older than

controls, and research suggests there is consistent decline in new learning abilities with increasing age, as well as some decline in retrieval of newly learned material (Bigler, 2012). It is possible that age-related differences were detected in studies that were weak in methodological quality, providing misleading results.

There was preliminary support to suggest that caregivers' vocabulary decreased more rapidly over time than that of controls (Vitaliano et al., 2005). Since groups were matched closely on age, and research suggests vocabulary remains stable into advanced age (Bigler, 2012), this finding was particularly interesting. Unfortunately, only two studies measured vocabulary, and as such drawing conclusions would be premature. As with any cognitive ability, evidence suggestive of impairment should be demonstrated across a range of tests and studies, to ensure that a specific ability is being measured accurately.

Evidence to suggest that caregivers of PWD experienced deficits in executive functioning was poor. Whilst significant results were reported, findings were reported by studies considered to be at high risk of bias. Those studies considered to be more robust in design did not report significant differences between groups.

There was evidence to suggest that caregivers of PWD performed better than non-caregivers in some areas of cognitive ability. Caregivers of PWD had better processing speed than controls, and performed better than controls on one measure of delayed verbal memory (O'Sullivan et al., 2018). These findings contradict the trend of the review, and were not support by studies implementing the same tests and rated of a similar methodological quality (de Vugt et al., 2006). Interestingly, a number of studies have reported better health outcomes for older caregivers, when compared to non-caregivers (Brown et al., 2009; Fredman, Doros, Ensrud, Hochberg, & Cauley, 2009; Park-Lee, Fredman, Hochberg, & Faulkner, 2009). Older adult caregivers have been

found to physically healthier (McCann, Hebert, Bienias, Morris, & Evans, 2004), and have lower rates of mortality (Brown et al., 2009) and functional decline (Fredman et al., 2009) than non-caregivers. Furthermore, Bertrand et al. (2012) found that full-time female caregivers had better memory performance and processing speed than people who did not provide care, suggesting that caregiving may help to preserve cognitive abilities. Research suggests that challenging one's cognitive abilities slows the rate of cognitive decline (Hall et al., 2009; Wilson et al., 2002), and as such complex cognitive demands, which increase with the duration of caregiving (Leipold, Schacke, & Zank, 2008), may help to preserve cognitive health.

Finally, consideration should be given to results suggesting consistent deficits in younger caregivers' cognition when compared to matched controls (Corrêa et al., 2016). These findings are of interest because most studies examine older caregivers of PWD, who are more likely to experience age-associated decline in cognition (Salthouse & Davis, 2006). Younger caregivers are less likely to experience age-associated vulnerabilities and as such cognitive implications can be assessed more clearly. Unfortunately the study that including young caregivers was not considered to be of high quality and as such findings should be interpreted with caution.

Limitations

In the studies included in the review, limitations included the use of non-random sampling, consistent lack of reporting on power analysis and the cross-sectional nature of the majority of studies, which means that causality cannot be ascertained. Furthermore, the range of tests used to assess specific cognitive abilities was limited and restricted conclusions being drawn from the review. Attention was the only

construct where ranges of cognitive abilities were adequately measured and illustrated consistent support across studies.

The scope of the review was limited to only including papers that were written in English. Further increasing the risk of bias was the absence of a second reviewer as well as the risk of publication bias (Easterbrook, Gopalan, Berlin & Matthews, 1991). The review only looked at papers from the year 2000 onwards, to account for the ever-evolving evidence base. This potentially contributed to only 14 studies meeting the review criteria. Consequently, the review was limited by failing to have sufficient quality data to draw strong conclusions and resulted in the review concluding that more quality research is needed. This means that the conclusions drawn from the review are unlikely to have a significant impact on influencing healthcare quality in current practice.

Future Research

Future research would benefit from the implementation of a battery of robust measures of cognitive ability, which would provide normative data on the "oldest old" and allow for appropriate comparisons to be made in the ageing population. Research to clarify preliminary findings that indicate deficits in memory would be advantageous as well as longitudinal study designs to establish whether changes in cognitive ability continue to decline in accordance with years of caregiving, or whether recovery from reduced cognitive functioning is possible. In addition, future research could focus on interventions that can be used to assess whether reductions in carers' stress are accompanied in improved caregivers' attention. Whilst meditation and cognitive behavioural therapy have been found to reduce stress and improve cognitive

performance in caregivers of PWD (Mackenzie, Wiprzycka, Khatri, & Cheng, 2013), their specific impact on attention is unknown.

In clinical practice, professionals should be aware of potential attention difficulties in caregivers of PWD. This could cause a host of problems related to care planning. Professionals should consider delivering information in formats that do not overwhelm caregivers, considering time, environment and method of communication. Written summaries, reminders and the encouragement of attending to important tasks in environments with minimal distraction may support caregivers to carry out their roles more effectively and for the longer term.

Conclusions

This review highlighted that the limited research into caregivers' cognitive abilities is characterised by methodological weakness, preventing definitive conclusions from being drawn. Despite this, there is some evidence indicative of serious concern. Early research findings suggest that caregivers' attentional abilities are compromised, which could influence the wellbeing of the caregiver and the care recipient. Further research is required to better understand the impact of impaired attention on the caregivers' role, and the influence of this on future care planning.

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Empirical Research

Perceived Suffering and Depression in Dementia Caregivers: The Role of Compassion and Intrusive Thoughts

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Abstract

Objectives: Research indicates perceived suffering in a care recipient is closely related to caregivers' experience of depressive symptoms. More recently, findings suggest that intrusive thoughts have a mediating role between perceived suffering and depressive symptoms in caregivers of people with dementia (PWD). The current study aims to replicate these findings, in an effort to support emerging theory and the development of psychological interventions. Additionally, compassion towards another in a caregiving relationship (i.e. 'other-compassion') has recently been identified as a risk factor for depressive symptoms amongst caregivers of PWD. The current study expands on these findings by exploring the role of self and other-compassion as a moderator between the variables.

Method: A cross-sectional, within-subjects design was used to recruit 368 caregivers of PWD to the study. Participants completed six standardised self-report questionnaires online. Mediation and moderated mediation analysis was conducted using the PROCESS macro for SPPSS.

Results: There was a significant indirect effect of perceived physical and psychological suffering on depressive symptoms, via intrusive thoughts. Neither self-compassion nor other-compassion was found to moderate the relationship between perceived suffering and intrusive thoughts. As such, moderated mediation did not occur.

Conclusion: The current study highlights intrusive thoughts as a potential pathway to depressive symptoms for caregivers of PWD. Research findings support the implementation of interventions targeted at intrusive thoughts, and refute concerns regarding the role of compassion-focused interventions. Clinical implications and directions for future research are discussed.

Keywords: compassionate, intrusion, dementia, caregiving, suffering

Caregivers of people with dementia (PWD) are at increased risk of psychological and physical health problems, including psychiatric morbidity and mortality (Capistrant et al., 2012; Klein et al., 2014; Perkins et al., 2013). Findings suggest that amongst caregivers of PWD, perceptions of suffering and intrusive thoughts play a key role in caregivers' mental health (Schulz, Savla, Czaja, & Monin, 2017). Research also suggests that trait compassion may be a significant risk factor for depressive symptoms (Schulz et al., 2017). Given that caregivers of PWD are a growing population, and that a deterioration in mental health is associated with elder neglect and abuse (Kohn & Verhoek-Oftedahl, 2011), this area of interests warrants further exploration.

A small number of studies highlight a relationship between perception of suffering in the care recipient and caregivers' emotional distress (Schulz et al., 2009, 2008). Recently, intrusive thoughts have been found to have a mediating role between perceived suffering and depression in caregivers of PWD (Schulz et al., 2017). These findings could have significant clinical implications, given that the prevalence of depression amongst caregivers of PWD ranges between 22-70% (Bednarek et al., 2016; Omranifard, Haghighizadeh, & Akouchekian, 2018). As such, the current study aims to replicate the above findings, ensuring the development of target interventions are adequately informed.

Furthermore, findings also suggest that trait compassion may be a significant risk factor for depressive symptoms in caregivers of PWD (Schulz et al., 2017). These findings are in contrast to a growing body of research which suggests compassionate interventions have positive outcomes, including reduced feelings of shame, self-

criticism, stress, depression and anxiety (Gilbert & Procter, 2006; Judge, Cleghorn, McEwan, & Gilbert, 2012). The disparity between research findings is perhaps explained by the development of the construct 'compassion', and how it has evolved in research over time. The construct of compassion is often conceptualised as a single entity, despite recent research highlighting that self-compassion and other-compassion are distinct constructs, which are not significantly related (López, Sanderman, Ranchor, & Schroevers, 2018). As such, interpretation of the literature should be made with caution and future research should strive to study the constructs separately.

Self-compassion is commonly conceptualised as an attitude that is relevant to one's personal experience of suffering; it encompasses self-kindness, a sense of common humanity, and mindfulness (Neff, 2003). Higher levels of self-compassion have been associated with reduced stress, anxiety and depressive symptoms (Bluth & Neff, 2018; Macbeth & Gumley, 2012; Marsh, Chan, & MacBeth, 2018). Amongst caregivers, self-compassion is associated with reduced caregiver burden (Lloyd, Muers, Patterson, & Marczak, 2019), increased life satisfaction (Neff & Faso, 2015), and the delivery of compassionate care (Beaumont, Durkin, Martin, & Carson, 2016).

Theoretical findings have led to the development and implementation of self-compassionate interventions, which provide compelling evidence regarding the benefits of cultivating traits in self-compassion for a range of disorders (Ashworth, Gracey, & Gilbert, 2011; Kelly & Carter, 2015; Lucre & Corten, 2013) across older adult populations (Perez-Blasco, Sales, Meléndez, & Mayordomo, 2016) and in caregivers or people with dementia (Collins, Gilligan, & Poz, 2018; Danucalov, Kozasa, Afonso, Galduroz, & Leite, 2017). In family caregivers of people with Alzheimer's disease, research has found fostering traits in self-compassion was associated with significant improvements in vitality, attention and quality of life

(Danucalov et al., 2017), as well as reduced anxiety and depression (Collins et al., 2018).

Theoretical understandings of the mechanisms that underpin the observed benefits of self-compassion for caregivers of PWD are ambiguous. One potential pathway through which self-compassion could act as a defence against poor psychological wellbeing is through coping style. Individuals with greater levels of self-compassion demonstrated more emotion-focused coping, less avoidance-orientated coping (Neff, Hsieh, & Dejitterat, 2005, Thompson & Waltz, 2008), and have fewer negative thinking styles, such as self-judgment and rumination (Leary, Tate, Adams, Batts Allen, & Hancock, 2007). Recently, these relationships were evidenced in a population of caregivers, whereby self-compassion was negatively correlated with dysfunctional coping strategies, and positively correlated with emotion-focused coping strategies (Lloyd et al., 2019). As emotion-focused coping strategies have been associated with lower levels of anxiety and depression in caregivers of PWD (Cooper, Katona, Orrell, & Livingston, 2008; Kneebone & Martin, 2003), it is possible that self-compassion influences some aspect of emotion regulation, and thus psychological wellbeing.

As well as self-compassion, compassion towards others (other-compassion) has been extensively investigated in relation to psychological wellbeing. Other-compassion is defined as a feeling that arises when witnessing suffering, which subsequently motivates a desire to help (Goetz, Keltner, & Simon-Thomas, 2010). It is widely accepted that traits in other-compassion are an adaptive evolutionary response, safeguarding off spring survival by ensuring the presence of suffering is identified and reduced (Goetz et al., 2010; López et al., 2018).

High levels of other-compassion have been associated with reduced depressive symptoms and negative affect (Stuntzner, 2014; Taylor & Turner, 2001), as well as increased self-esteem (Krause & Shaw, 2000), self -reported happiness (Mongrain, Chin, & Shapira, 2011) and positive affect (Klimecki, Leiberg, Lamm, & Singer, 2013). In a similar vein, intervention studies provide persuasive evidence, indicating other-compassion increases positive affect (Klimecki et al., 2013) and self-reported happiness (Mongrain et al., 2011).

Despite encouraging potential, research exploring the role of other-compassion in caregivers of PWD is still emerging. Interestingly, recent findings unexpectedly reported other-compassion was a risk factor for poor psychological wellbeing (Schulz et al., 2017). Other-compassion was found to heighten caregivers' perception of their loved ones' suffering, leading to an increase in the experience of intrusive thoughts and subsequently depressive symptoms (Schulz et al., 2017). Associations between perceived suffering and caregiver depression (Gao, Chan, & Mao, 2009; Schulz et al., 2008; Tang et al., 2013) and between intrusive thoughts and psychological distress (Baum, Cohen, & Hall, 1993; Park, 2010; Watkins, 2008) have been well documented; however, there is little research exploring the relationship between other-compassion in the activation of intrusive thoughts (Schulz et al., 2017).

Intrusive thoughts are defined as cognitions or images that are spontaneous, disruptive, difficult to control and unwanted (Rachman, 1981). Research suggests that many caregivers experience intrusive thoughts (Stjernswärd & Östman, 2008), and the ability to control unwanted thoughts has a significant impact on caregiver self-efficacy and bereavement outcomes (Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001; Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002).

Although supporting literature is sparse, findings reported by Schulz et al. (2017) make intuitive sense, given that individuals with high traits of other-compassion will likely be more sensitive to the care recipients' suffering, and thus experience more unwanted thoughts about suffering, or find intrusions more upsetting. Findings reported by Schulz et al. (2017) highlight the unexpected nature of this relationship and subsequently call into question the role of self-compassion, given it is a construct that is closely related to other-compassion.

Little is known about the relationship between self-compassion and intrusive thoughts in caregivers of PWD. To the authors' knowledge, there is no research to date that has explored this relationship; however there is a growing body of research supporting the development of theory surrounding a relationship between self-compassion and rumination. Rumination is a construct that is closely related to intrusive thoughts (Speckens, Ehlers, Hackmann, Ruths, & Clark, 2007) and involves the engagement of unwanted repetitive thinking (Speckens et al., 2007). Given that intrusive thoughts describes the presence and occurrence of unwanted thoughts and images, theory surrounding self-compassion and rumination may help to inform hypotheses related to self-compassion and intrusive thoughts.

In non-clinical populations, individuals with low levels of self-compassion have been found to be more likely to ruminate than individuals with high levels of self-compassion (Neff, 2003; Neff & Vonk, 2009). In addition, intervention studies have similarly reported that individuals who were able to cultivate traits in self-compassion were more likely to experience a reduction in ruminative thinking and depressive symptoms (Neff, Kirkpatrick, & Rude, 2007). Beyond correlation analysis, recent research involving undergraduate students reported a moderating effect of self-compassion, illustrating self-compassion weakened the relationship between stress

and ruminative thinking (Samaie & Farahani, 2011). Taken cumulatively, these findings provide a persuasive argument regarding the protective nature of self-compassion against rumination, and support the hypothesis that self-compassion likely has a protective role against the experience of intrusive thoughts in caregivers of PWD.

In summary, although it is widely assumed that compassion is a protective trait, recent research questions this assumption in a population of caregivers of PWD. The current study aims to replicate results illustrated by Schulz et al. (2017) and expand their findings to explore the role of self-compassion. It is hypothesised that intrusive thoughts will mediate the relationship between perceived suffering and depressive symptoms amongst caregivers of PWD. Furthermore, the mediating effects of intrusive thoughts will be moderated by compassion. It is expected that other-compassion will increase the mediating effects of intrusive thoughts on depressive symptoms, while self-compassion will reduce the mediating effects of intrusive thoughts on depressive symptoms. With the growing implementation of compassion-focused interventions, clarity regarding the role of compassion for caregivers of PWD is essential.

Methods

Design

The study used a cross-sectional, within-subjects design. Participants completed six standardised self-report questionnaires measuring depressive symptoms, perceived suffering (physical/ psychological), intrusive thoughts, and compassion (other/self).

Participants

Participants were required to be at least 18 years of age, be providing care within the care recipient's home environment and understand written English. In total, 373 participants took part in the study. Preliminary analysis identified and removed five outliers, thus the final analyses is based on 368 participants. There was a wide range of ages (min = 23; max = 87; mean = 56; SD = 12.99), 94.6% were female and 50.8% were within the 46-60 age bracket. *A priori* power calculations were made using G*Power. Estimates suggested that 160 participants were needed in order to detect a medium effect size, using 8 predictors at an alpha level of .05 (p <.05) and a power of .80.

Procedure

The study protocol and all study materials were reviewed and approved by the University of Edinburgh Ethics Committee (Appendix F). The study was advertised online using social media, support pages and support forums (Appendix G). The full aims and timings of the study were outlined on an information sheet before participants provided consent to take part. Participants were only able to access the survey after they ticked a box to provide consent. Participants were informed they could discontinue at any time; following completion of the study, however, they were informed that it would not be possible to subtract individual datasets, for anonymity reasons.

Measures

Participants completed demographic information and a series of standardised measures.

Depressive Symptoms

The *Patient Health Questionnaire (PHQ-9)* was used to assess depressive symptoms in caregivers. The PHQ-9 used nine items to assess the extent to which the participant experienced symptoms of depression in the past two weeks (e.g. feeling down, depressed or hopeless, poor appetite or overeating). The measure used a 4-point scale ranging from 0 (not at all) to 3 (nearly every day). The PHQ-9 demonstrates good internal consistency (Cronbach's alpha = 0.88) (Kroenke, Spitzer, & Williams, 2001) and is strongly correlated with Becks Depression Inventory – II (r =.77) (Kung et al., 2013).

Perception of Suffering

In line with Schulz et al. (2017), caregivers' perception of the care recipients' suffering was assessed using the *Experience of Suffering Scale (*ESS; Schulz et al., 2010). The ESS yields two separate scales, measuring physical suffering (ESS-Ph) and psychological suffering (ESS-Ps).

The physical suffering (ESS-Ph) scale comprises nine items. For each item, the caregiver was asked to give their best estimate of how often the care recipient experienced each of the nine symptoms (e.g. shortness of breath, pain, nausea, fatigue) during the past week, using a 4-point scale from 0 (not at all) to 3 (very often/every day). Scores were calculated by summing all items, with higher scores indicating higher perceived physical suffering. The ESS-Ph demonstrates good internal consistency (Cronbach's alpha = 0.64) (Schulz et al. 2010).

The psychological suffering (ESS-Ps) scale comprises 15 items, rating psychological symptoms over the past week. For each item, the caregiver was asked how often the care recipient experienced each of the 15 feelings during the past week

(e.g. afraid, depressed, hopeless), along the same 4-point rating scale. The EES-Ps was computed by summing all 15 items, with higher scores indicating higher perceived psychological suffering. The ESS-Ps demonstrates good internal consistency (Cronbach's alpha = 0.89) (Schulz et al. 2010).

Intrusive Thoughts

In line with Schulz et al. (2017), an adapted version of the *Impact of Events Scale (*IES-A; Schulz et al., 2017) was used to measure caregivers' experience of intrusive thoughts. The IES-A only included items related to the intrusion subset of the *Impact of Events Scale* (IES, Horowitz, Wilner, & Alvarez, 1979) (items 1, 4, 5, 6, 10, 11, 14) and omitted items related to the avoidance subset (items 2, 3, 7, 8, 9, 12, 13, 15). The wording of each item substituted the word 'it' to 'my loved one's illness' for each item. The scale assessed the extent to which caregivers were unable to inhibit thoughts about the care recipient's illness (e.g. I thought about my loved one's illness when I did not mean to, I had dreams about my loved one's illness). Responses ranged from 0 (not at all) to 3 (often). A total score was provided, with higher scores indicating an inability to suppress intrusive thoughts. The IES-A demonstrates good internal consistency (Cronbach's alpha =0.79) (Schulz et al., 2017).

Other-compassion

In line with Schulz et al. (2017), the *Caregiver Compassion Scale (CGCS;* Feeney & Collins, 2001, 2003) was used to measure compassion towards the care recipient (i.e. other-compassion). The CGCS consists of 11 items that assess the extent to which the caregiver agreed or disagreed with feelings of compassion towards the care recipient (e.g. it is difficult for me to see my partner/relative suffer, it is important for me to try

to do everything possible to help reduce the suffering of my partner/relative). Each item is rated on a 5-point scale from 0 (strongly disagree) to 4 (strongly agree). The CGSC demonstrates good internal consistency (Cronbach's alpha = 0.79) (Schulz et al., 2017).

Self-compassion

The *Self-Compassion Scale –Short form* (SCS-SF, Raes, Pommier, Neff, & Van Gucht, 2011) was used to measure compassion towards the self. The SCS-SF consists of 12 items assessing how individuals typically act towards themselves during difficult times. Each item is rated on a 5-point scale from 0 (never) to 4 (always), allowing a total self-compassion score to be calculated. The SCS-SF has good validly, reliability and internal consistency (Cronbach's alpha = 0.86), and has a near perfect correlation with the long form SCS (r=.96) (Raes et al., 2011).

Analytic Approach

All analyses were conducted using SPSS. Planned analyses included descriptive data, covariate analysis, correlational analyses, mediation and moderated mediation.

To run the mediation and moderated mediation analysis, the PROCESS macro for SPPSS was used (Hayes, 2013). Indirect and direct effects were computed and reported with 95% confidence interval. Model 1 was used to test simple mediation. Model 7 was implemented to test moderated mediation.

Results

The data was checked for multicollinearity, linearity and homoscedasticity. Assumptions for parametric analysis were met, except for depressive symptoms (PHQ-9) and intrusive thoughts (IES-A), which showed negative kurtosis. There were

no missing data as the online protocol prevented participants from submitting incomplete questionnaires.

Sample Characteristics

In total, 368 participants were included in the study. The majority of participants were caring for a parent/ step-parent (55.4%) and 43.2% had been caring for 0-1 years. Table 1 outlines the frequencies of the demographic data.

Table 1

Participant Characteristics

Characteristic	Sample	%

Gender:		
Female	348	94.6
Male	20	5.4
Age:		
18-29	7	1.9
30-45	37	10.1
46-60	187	50.8
61-75	105	28.5
76-90	32	8.7
Marital status:		
Single	46	12.5
Married/civil partner/co-habiting	278	75.5
Divorced/separated	35	9.5
Widowed	4	1.1
Prefer not to say	5	1.4
Educational attainment:		
Primary school	1	.3
Secondary school/high school	93	25.3
College	128	34.8
University degree/masters/PhD	142	38.6
Prefer not to say	4	1.1
Relationship to the care recipient:		
Husband/wife/partner	125	34.0
Parent/step parent	204	55.4
Extended family member	27	7.3
Friend	1	.3
Other	11	3
Care recipient's stage of dementia:		
Early	42	11.4
Middle	244	66.3
Late	82	22.3
Length of time in years providing care:		
0-2	159	43.2
3-4	110	29.9
5-6	55	14.9
7+	44	12

Descriptive Analyses

Mean and standard deviation results are depicted in Table 2. Mean results showed that participants fell within the moderate range for depressive symptoms. 22.5% (n=83) of the sample reported experiencing clinically severe levels of depression (PHQ-9 $\geq$ 20).

Table 2

Descriptive Statistics for Predictor and Outcome Variables

Variable	Possible range	Min	Max	Mean	SD
ESS-Ph	0-27	1	24	12.22	4.48
ESS- Ps	0-45	0	39	17.96	8.13
IES-A	0-21	4	21	15.45	4.15
PHQ-9	0-27	0	27	13.6	6.81
SCS-S	0-48	10	42	25.99	5.64
CGCS	0-44	21	44	34.09	4.81

Note. ESS-Ph: Experience of Suffering Scale- Physical, ESS-Ps: Experience of Suffering Scale- Psychological, IES-A: Impact of Events Scale- Adapted, PHQ-9: Patient Health Questionnare-9, SCS-S: Self-compassion Scale-Short, CGCS: Caregivers Compassion Scale

Non-parametric tests were used to explore group differences. Females (median =14) were significantly more depressed than males (median = 7), U = 2194, z = -2.78, p = .005. According to a Kruskal-Wallis test, depressive symptoms were significantly affected by age, H (4) = 14.23, p = .007. Pairwise comparisons with adjusted p-values showed that there was a significant difference between depressive symptoms in individuals aged 46-60 compared to individuals ages 76-90 (p = .050), with younger adults experiencing more depression. A Kruskal-Wallis test showed that depressive symptoms were not significantly affected by the care recipient's stage of dementia, H (2) = 5.98, p = .05, or length of time spent caring, H (3) = .18, p = .98.

Correlation Analysis

Spearman's rho correlations were implemented to assess associations between study variables. The results, displayed in Table 3, show a pattern of weak to moderate correlations in the predicted directions. There was a strong correlation between the number of depressive symptoms and intrusive thoughts (.52; p <. 01). Perceived physical suffering was not significantly correlated with self-compassion (.07; p=. 16). Age was negatively associated with perceived physical suffering (-.16; *p* =. 003), perceived psychological suffering (-.18, *p* <. 001) and other-compassion (-.18, p = .001). Gender and stage of dementia were also found to correlate with outcome variables. Time spent caring did not correlate with outcome variables.

Table 3

Correlation Matrix between Variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Time	1									
2. Age	.186**	1								
3. Gender	.056	.179**	1							
4. Stage	.269**	.021	.081	1						
5. ESS:Ph	.003	-.155**	-.003	.202**	1					
6. ESS:Ps	-.01	-.183**	.029	.046	.443**	1				
7. IES-A	.008	-.112	.115*	.129*	.232**	.322**	1			
8. PHQ-9	.003	-.192**	.145**	.127*	.267**	.372**	.515**	1		
9. SCS-S	-.029	-.065	.120*	-.065	0.073	.260**	.205**	.394**	1	
10. CGCS	-.027	-.182**	-.006	.047	.318**	.428**	.284**	.199**	.197**	1

Note. All correlations are Spearman's rho, n=368. ESS: Experience of Suffering Scale, ESS:Ph = Physical Suffering, ESS: Ps = Psychological Suffering, IES-A: Impact of Events Scale- Adapted, PHQ-9: Patient Health Questionnare-9, SCS-S: Self-compassion Scale-Short, CGCS: Caregivers Compassion Scale

** < .01, *< .05

Direct and Indirect Effects of Perceived Suffering on Depressive Symptoms via Intrusive Thoughts

Mediation analysis was used to test the direct effect of perceived suffering (physical/psychological) on depressive symptoms, as well as the indirect effect of intrusive thoughts on depressive symptoms. Results are displayed in Table 4, detailing the coefficients and bootstrapped confidence intervals (BCI). Numbers in each row are BCI of 5000 resamples. If confidence intervals do not contain zero, the effect of the path is considered to be significant at a *p* value of less than .05. The overall variance explained by each model is shown.

Analysis was conducted controlling for age, gender and stage of dementia. Results showed there was a significant indirect effect of perceived physical suffering on depressive symptoms through its relationship with intrusive thoughts, $b = .135$, 95% BCI [.058, .212]. Mediation analysis also showed there was a significant indirect effect of perceived psychological suffering on depressive symptoms through its relationship with intrusive thoughts, $b = .097$, 95% BCI [.056, .145]. The introduction of a mediator allowed for a total of 30% and 33% of variance to be explained in perceived physical and psychological suffering, respectively.

Table 4

Direct and indirect effects of mediation analysis

	b	BCI	
		LL	UL
Physical suffering			
Total effect	.36	.21	.51
Direct effect	.23	.09	.37
Indirect effect	.13	.06	.21
Psychological suffering			
Total effect	.29	.21	.37
Direct effect	.19	.12	.27
Indirect effect	.1	.06	.15

Compassion as a Moderator of the Mediated Relationship between Perceived Suffering and Depressive Symptoms via Intrusive Thoughts

Moderated mediation was used to estimate the direct effect of perceived suffering on depressive symptoms, as well as the conditional effect of other-compassion and self-compassion on the relationship between perceived suffering and intrusive thoughts. Age, stage of dementia and gender were controlled for in all the analyses.

It was hypothesised that the relationship between perceived suffering and intrusive thoughts would be moderated by compassion (other/self), such that the negative effects of perceived suffering and intrusive thoughts would be heightened at higher levels of other-compassion, and buffered against at higher levels of self-

compassion. Table 5 details the results. Diagrammatic representations of the models are depicted in Figures 1-4 (Appendix H).

Perceived Physical Suffering

Moderated mediation was used to test if intrusive thoughts mediated the association between perceived physical suffering and depressive symptoms, while simultaneously testing if this mediation was moderated by other-compassion. The total model explained 30% of the variance in depressive symptoms, R^2 = .3, p <.0001, f = 31.54. Perceived physical suffering directly predicted depressive symptoms, t (362) = 3.2, p = .001; however, there was no interaction between perceived physical suffering and other-compassion when predicting intrusive thoughts, t (361) = 1.07, p =. 29; test of highest order unconditional interaction: R^2 = .0027, p = .29, f = 1.12. As such, moderated mediation did not occur: Index of Moderated Mediation = .0071, 95% BCI [-.007, .02].

The model was repeated, exploring self-compassion as the moderator. Perceived physical suffering directly predicted depressive symptoms, t (362) = 3.2, p = *.001*, however there was no interaction between perceived physical suffering and self-compassion when predicting intrusive thoughts: t (361) = -.46, p =. 65; test of highest order unconditional interaction: R^2 = .0005, p = .64, f = .21. As such, moderated mediation did not occur: Index of Moderated Mediation = -.0028, 95% BCI [-.0157, .0078].

Perceived Psychological Suffering

Moderated mediation was used to test if intrusive thoughts mediated the association between perceived psychological suffering and depressive symptoms, while

simultaneously testing if this mediation was moderated by other-compassion. The total model explained 33% of the variance of depressive symptoms, R^2 = .33, *p* <. 0001, *f* = 35.74. Perceived psychological suffering directly predicted depressive symptoms. Perceived psychological suffering directly predicted intrusive thoughts, t (361) = 3.87, p <. 001; however, there was no interaction between perceived psychological suffering and other-compassion when predicting intrusive thoughts: t (361) = -1.68, p =. 09; test of highest order unconditional interaction: R^2 = .0055, *p* = .093, *f* = 2.83. As such, moderated mediation did not occur: Index of Moderated Mediation = -.006, 95% [BCI = -.014, .0017].

The model was repeated, exploring self-compassion as the moderator. Perceived psychological suffering directly predicted depressive symptoms. Perceived psychological suffering directly predicted intrusive thoughts, t (361) = 4.65, p <.001; however, there was no interaction between perceived psychological suffering and self-compassion when predicting intrusive thoughts: t (361) = .38, p =. 7; test of highest order unconditional interaction: R^2 = .0003, *p* = .7, *f* = .144. As such, moderated mediation did not occur: Index of Moderated Mediation = -.0001, 95% BCI [-.004, .0059].

Table 5

Compassion as a moderator of the mediated relationship between perceived suffering and depressive symptoms via intrusive thoughts

	Path	Other-compassion			Self-compassion		
		b	BCI		*b*	BCI	
			LL	UL		LL	UL
Physical suffering	Direct effect of PS on IT	.11	.01	.20	.17	.08	.27
	Direct effect of compassion to IT	.24	.15	.33	.14	.07	.22
	Interaction of PS with compassion on IT	.01	-.008	.03	-.003	-.02	.01
	Direct effect of PS on DS	.23	.09	.37	.23	.09	.37
	Direct effect of IT on DS	.73	.58	.87	.72	.56	.87
	Index of moderated mediation		-.01	.02		-.016	.008
Psychological suffering	Direct effect of PS on IT	.11	.05	.16	.12	.07	.18
	Direct effect of compassion to IT	.18	.09	.28	.11	.03	.18
	Interaction of PS with compassion on IT	-.009	-.02	.001	.001	-.006	.009
	Direct effect of PS on DS	.19	.12	.27	.19	.12	.27
	Direct effect of IT on DS	.66	.52	.81	.66	.52	.81
	Index of moderated mediation		-.014	.001		-.004	.006

Note. DS = depressive symptoms, IT = intrusive thoughts, PS = perceived suffering

Discussion

The aim of the study was to replicate and expand on findings reported by Schulz et al. (2017). The study found that perceived suffering was significantly related to depressive symptoms in caregivers of PWD, and intrusive thoughts partially mediated this relationship. Neither other- nor self-compassion was found to moderate the relationship between perceived suffering (whether physical or psychological) and intrusive thoughts, and as such moderated mediation did not occur.

Initial findings are consistent with previous research (Schulz et al., 2017) validating the recognition of perceived suffering as a contributing factor to caregiver wellbeing, as well as supporting the advance of psychological theory regarding the critical role of intrusive thoughts. There was greater mediation for the relationship between perceived psychological suffering and depressive symptoms compared to perceived physical suffering. This difference could be explained by the measures implemented, whereby the psychological suffering subscale provided more opportunity to identify and acknowledge distress, due to the larger number of questions in the measure. It is possible that the broader range of questions was more effective at capturing a relationship with intrusive thoughts, and thus was illustrated in the analysis.

Moreover, it is possible that greater mediation occurred for perceived psychological suffering compared to physical suffering as a result of caregivers' appraisals of competing demands. The task-orientated nature of alleviating physical suffering means that caregivers may perceive themselves as more adequately fulfilling their role by carrying out practical and tangible duties. Moreover, it could be that caregivers prioritise practical needs, leaving little time to meet psychological demands, or that caregivers feel unequipped to deal with psychological distress. If caregivers perceive themselves as being less competent in meeting psychological needs, they are

more likely to experience difficult emotions related to this aspect of their role, thus heightening the experience of intrusive thoughts.

The second half of the study explored the role of compassion as a moderator of the relationship between perceived suffering and intrusive thoughts. Other-compassion was not found to moderate the relationship between perceived physical suffering and intrusive thoughts, which was inconsistent with findings reported by Schulz et al. (2017). The difference in findings might be explained by a number of reasons. In the previous study, the researchers did not control for stage of dementia. This may have confounded the results, as a period of adjustment and acceptance would be expected following a more recent diagnosis. Furthermore, the sample population of the Schulz et al. (2017) study was uniquely compromised of two minority groups, African Americans and Hispanics. Although other-compassion is an adaptive universal trait, ethnicity has been associated with a number of other variables, such as family and socio-economic situation (Connelly, Gayle, & Lambert, 2016), and as such the sample population may have subtly influenced the study's findings. As the current study did not measure ethnicity, a comparison controlling for ethnicity was not possible.

Despite the insignificant findings regarding other-compassion as a moderator, the current study's findings can be used to support claims that highlight traits in other-compassion likely reflect a high quality, secure relationship between the PWD and the caregiver (Mikulincer & Shaver, 2005). In addition, in the absence of other-compassion as a risk factor, research highlighting other-compassion as a protective trait can be more strongly upheld. Indeed research suggests other-compassion reduces the experience of burn-out (Lamothe, Boujut, Zenasni, & Sultan, 2014), and improves positive affect, wellbeing and resilience (Cosley, McCoy, Saslow, & Epel, 2010; Evans & Steptoe, 2001).

The hypothesised relationship between self-compassion and intrusive thoughts was not supported: self-compassion did not moderate the relationship between perceived suffering and intrusive thoughts. These findings suggest the reported benefits of self-compassionate interventions for caregivers of PWD (Collins et al., 2018; Danucalov et al., 2017) are unlikely to help caregivers by acting on the relationship between perceived suffering and intrusive thoughts. Given these findings, it may be that a different model would have been better suited to the current study design. It is possible that self-compassion may benefit caregivers, instead, by acting on the relationship between intrusive thoughts and psychological distress (PROCESS Model 14). As previously cited, a growing body of research highlights that self-compassion facilitates the use of adaptive emotion regulation strategies, particularly in terms of positive reframing (Allen & Leary, 2010), greater emotional acceptance (Finlay-Jones, Rees, & Kane, 2015), and increased tolerance of negative emotions (Inwood & Ferrari, 2018). As such, self-compassion may enable caregivers to down regulate the experience of intrusive thoughts, allowing them to compassionately experience and process emotions, thus decreasing depressive symptoms (Svendsen et al., 2016). Future research would benefit from additional cross-sectional, theory-driven survey work to test this model.

The current findings have a number of important clinical implications. The study highlights the fact that perceived suffering and caregiver wellbeing are closely intertwined, and as such, target interventions should act on alleviating care recipient suffering, which should at the same time improve caregiver outcomes. Regular health checks, ensuring adherence to medication and improvements to the care recipient's environment are examples of strategies which could be used to promote the shared benefit of reduced suffering.

Furthermore, the mediating role of intrusive thoughts suggests caregivers may benefit from psychological interventions aimed at cultivating adaptive emotion-focused coping strategies, such as acceptance and positive restructuring. Research has shown emotion-focused coping strategies are associated with lower levels of burden and higher quality of life for caregivers of people with dementia (Hlabangana & Hearn, 2019; Lloyd et al., 2019). As such, harnessing such strategies may increase tolerance of unwanted thoughts and reduce the desire for caregivers to supress intrusive thoughts, which ultimately increases their frequency (Salkovskis & Campbell, 1994).

There are several limitations with the study. Firstly, the research was conducted using an opportunity sample of self-identified caregivers, therefore there is likely to be a degree of self-selection bias. Furthermore, most of the participants were women, who despite being more likely to become caregivers (Sharma, Chakrabarti, & Grover, 2016) were disproportionately represented in the study.

Moreover, the cross-sectional study design means that conclusions regarding causation cannot be drawn. Thus, whilst intrusive thoughts were found to be a significant mediator between perceived suffering and depressive symptoms, it is possible that alternative models may exist that provide a good fit for the data.

The study also relied upon self-reported measures, and consequently could have been affected by socially desirable responding. The SCS-SF (Raes et al., 2011) was used to measure self-compassion, and is composed of three positive and negative subscales. It has recently been argued that the positive and negative items measure different aspects of self-compassion and therefore should not be combined to provide a total self-compassion score (López et al., 2015).

Future research would benefit from deepening the understanding of the role of intrusive thoughts, perhaps by building the evidence base for clear strategies that could

serve to reduce their occurrence. For example, strategies such as cognitive reappraisal or attentional deployment may help caregivers to tolerate distress, and thus reduce attempts of thought suppression.

Research would also benefit from investigating the interpersonal aspects of caregiving. An understanding of how distress is expressed differently within different types of caregiving relationships could be important for understanding suffering in both parties. It is possible that older adults who are dependent on their children for support may be more reluctant to fully disclose their suffering because they want to minimise the burden on their children. Equally, factors such as closeness and attachment are likely to interact with expressions of distress and suffering, as well as the caregiver's ability to identify and respond to perceptions of suffering.

To the authors' knowledge, this is the first piece of research to explore the relationships between self-compassion, perceived suffering and intrusive thoughts amongst caregivers of PWD. Whilst the study ruled out a moderating role for self- and other-compassion, the study builds on the emerging evidence base by advocating the mediating role of intrusive thoughts between perceived suffering and depressive symptoms. These findings provide clear direction for future research, and advocate the development of target interventions for caregivers of PWD.

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Appendices

Table of Appendices

Appendix A

PROSPERO Research Proposal

PROSPERO research strategy:

https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=112394

Appendix B

Quality Assessment Tool

A. STUDY INFORMATION

Reviewer:
Date Evaluated:

Paper being evaluated:
Year:
1st Author:
Journal, volume, pages:

B. PAPER QUALITY

QUALITIY ASSESSMENT TOOL FOR QUALITATIVE STUDIES
Effective Public Health Practice Project - adapted

COMPONENET RATINGS

A) SELECTION BIAS
(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1. Very likely
2. Somewhat likely
3. Not likely
4. Cant tell

(Q2) What percentage of selected individuals agreed to participate?

1. 80-100
2. 60-79
3. Less than 60
4. Not applicable
5. Cant tell

Rate this section	**STRONG**	**MODERATE**	**WEAK**

B) STUDY DESIGN
(Q1) Was the study design appropriate for the stated aim?

1. Yes
2. No
3. Cant tell

(Q2) Was a power calculation conducted?

1. Yes
2. No
3. Cant tell

Rate this section	**STRONG**	**MODERATE**	**WEAK**

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1. Yes
2. No
3. Cant tell

The following examples of cofounders

1. Race
2. Gender
3. Marital status
4. Age
5. SES
6. Education
7. Health status
8. Pre intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant cofounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1. 80-100
2. 60-79
3. Less than 60
4. Cant tell

Rate this section	**STRONG**	**MODERATE**	**WEAK**

D) BLINDING

(Q1) Was (were) the outcome assessors aware of the intervention or exposure status of participants?

1. Yes
2. No
3. Cant tell

(Q2) Were the study participants aware of the research question?

1. Yes
2. No
3. Cant tell

Rate this section	**STRONG**	**MODERATE**	**WEAK**

E) DATA COLLECTION METHODS

Psychometric adequacy

(Q1) Were data collection tools shown to be valid?

1. Yes
2. No
3. Cant tell

(Q2) **Were data collection tools shown to be reliable?**

1. Yes
2. No
3. Cant tell

Rate this section	**STRONG**	**MODERATE**	**WEAK**

Administration consistency

(Q1) Was the test administered by same person/ researcher across participants?

1. Yes
2. No
3. Cant tell

(Q2) Was the administrator appropriately trained to do so?

1. Yes
2. No
3. Cant tell

(Q3) Did testing conform to standardised procedures?

1. Yes
2. No
3. Cant tell

Rate this section	**STRONG**	**MODERATE**	**WEAK**

Health history

(Q1)Was data appropriately collected on the patient's history, considering factors that might impair cognition? (such as mood, fatigue, pain, head injuries, developmental; education and work history, past/present medical and psychiatric history, past/ present alcohol and substance abuse, past/presence medication)?

1. Yes
2. No
3. Cant tell

Rate this section	**STRONG**	**MODERATE**	**WEAK**

Overall rating for data collection:

Rate this section	**STRONG**	**MODERATE**	**WEAK**

F) WITHDRAWLS AND DROP OUTS

(Q1)Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

4. Yes
5. No
6. Cant tell
7. Not applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study (If the percentage differs by groups, record the lowest)

1. 80-100
2. 60-79
3. Less than 60
4. Cant tell
5. Not applicable

Rate this section	**STRONG**	**MODERATE**	**WEAK**

G) ANALYSES

(Q1) Are the statistic methods/choice of tests appropriate for the study design?

1. Yes
2. No

Rate this section	**STRONG**	**MODERATE**	**WEAK**

3. Cant tell

GLOBAL RATING

COMPONENET RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	Selection bias	Strong 1	Moderate 2	Weak 3
B	Study design	Strong 1	Moderate 2	Weak 3
C	Confounders	Strong 1	Moderate 2	Weak 3
D	Blinding	Strong 1	Moderate 2	Weak 3
E	Data collection methods	Strong 1	Moderate 2	Weak 3
F	Withdrawals and drop outs	Strong 1	Moderate 2	Weak 3

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	MODERATE	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1	Oversight
2	Differences in interpretation of criteria
3	Differences in interpretation of study

Final decision of both reviewers (circle one):

1	**STRONG**
2	**MODERATE**
3	**WEAK**

Component rating of study:

For each of the six components use the following descriptions as a road map.

A) SELECTION BIAS

Strong: The selected individuals are very likely to be representative of the target population (Q1 is 1) **and** there is a greater than 80% participation (Q2 is 1).
Moderate: The selected individuals are at least somewhat likely to be representative of the target population (Q1 is 1 or 2); **and** there is 60-79% participation (Q2 is 2). "Moderate" may also be assigned in Q1 is 1 or 2 and Q2 is 5 (cant tell).
Weak: The selected individuals are not likely to be representative of the target population (Q1 is 3); **or** there is less than 60% participation (Q2 is 3) **or** selection is not described (Q1 is 4); and the level of participation is not described (Q2 is 5).

B) STUDY DESIGN
Strong: Yes; yes sample size calculated and power stated in paper
Moderate: Yes; paper states sample size was conducted or there are more than 60 participants in each group
Weak: Yes/ No; no/cant tell; less than 60 in either group

C) CONFOUNDERS

Strong: will be assigned to those articles that controlled for at least 80% of relevant confounders (Q1 is 2); **or** (Q2 is 1).
Moderate: will be given to those studies that controlled for 60 – 79% of relevant confounders (Q1 is 1) **and** (Q2 is 2).
Weak: will be assigned when less than 60% of relevant confounders

D) BLINDING

Strong: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **and t**he study participants are not aware of the research question (Q2 is 2).
Moderate: The outcome assessor is not aware of the intervention status of participants (Q1 is 2); **or** the study participants are not aware of the research question (Q2 is 2); **or** blinding is not described (Q1 is 3 and Q2 is 3).
Weak: The outcome assessor is aware of the intervention

E) DATA COLLECTION METHODS

Psychometric adequacy
Strong: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have been shown to be reliable (Q2 is 1).
Moderate: The data collection tools have been shown to be valid (Q1 is 1); **and** the data collection tools have not been shown to be reliable (Q2 is 2) **or** reliability is not described (Q2 is 3).
Weak: The data collection tools have

Administration consistency:
Strong: NEU testing administered by same person, researcher had appropriately training to do so, testing environment limited distractions
Moderate: "cant tell" Q1,2,3
Weak: administrator varied, not appropriately qualified, testing environment was at home

Health history
Strong: IQ, present and historical psychological, medical and developmental histories taken into account
Moderate: IQ and some attempt to consider either psychological or medical influences
Weak: "cant tell" or "no"

Overall rating
Strong: Strong on all 2/3 items
Moderate: Strong/moderate on all items
Weak: Weak on 1 or more ratings

F) WITHDRAWALS AND DROP-OUTS - a rating of:
Strong: will be assigned when the follow-up rate is 80% or greater (Q2 is 1).
Moderate: will be assigned when the follow-up rate is 60 – 79% (Q2 is 2) **OR** Q2 is 5 (N/A).
Weak: will be assigned when a follow-up rate is less than 60% (Q2 is 3) or if the withdrawals and drop-outs were not described (Q2 is 4).

Appendix C

Summary of Neuropsychology Tests

Table 7

Summary of Neuropsychology Tests

Test	**Author**	**Description**	**Cronbach's alpha provided where available**
Abstraction (SILS)	(Zachary, 1986)	Task includes a sequence of numbers, letter or words that have their final element omitted. For each item, the respondent is required to complete the sentence.	.84 (Zachary, 1986)
Attentional network test	(Fan et al., 2002)	Participants were instructed to push either a left or right button depending on the orientation of the central of the 5 chevrons presented at variable intervals.	.87 (Fan et al., 2002)
Auditory verbal learning test	(Brand & Jolles, 1985)	Unrelated words are given and the participant must repeat the original list of 15 words immediately and then again after 30 minutes.	.77 (Geffen, Butterworth, & Geffen, 1994)
Category fluency task	(Lezak, Howieson, & Loring, 2012)	Participants named as many animals as possible in 60 s; the total score was the number of unique animals named in one minute.	(Lezak et al., 2012)(Lezak et al., 2012)(Lezak et al., 2012)(Lezak et al., 2012)(Lezak et al., 2012)
Choice reaction time test	(Michael O'Sullivan et al., 2018)(Michael O'Sullivan et al.,	Participants pressed and held a start key until either the word 'yes' or 'no' appeared on a screen; they then released the key and pressed a corresponding yes/no key before returning to the start key.	(Lezak et al., 2012)(Lezak et al., 2012)(Lezak et al., 2012)(Lezak et al.,

	2018)(Michael O'Sullivan et al., 2018)(O'Sullivan et al., 2018)		2012)
Colour trails test 1	(Maj et al., 1993)	Requires the participant to draw lines on a page following a number sequence quickly as possible.	.67 (D'Elia et al., 1996) (D'Elia et al., 1996)(D'Elia et al., 1996)(D'Elia et al., 1996)
Colour trails test II	(Maj et al., 1993)	The task is to follow a number series with a pencil, but to alternate between two colours.	.74 (D'Elia et al., 1996)
COWAT – animals; category fluency; F A S	(Benton, 1989)	List as many words as possible using the category outlined.	.7 (Ross, 2003)
CVLT-II	(Delis et al., 2000; Woods, Delis, Scott, Kramer, & Holdnack, 2006)	The experimenter reads a list of 16 nouns. Free and cued recall of list are tested immediately (short-delay), and again after 20 minutes (long-delay). In cued recall, the experimenter prompts the subjects with the word category.	.8 (Woods et al., 2006)
Digit span backwards (WAIS III)	(Wechsler, 1997)	The participant hears a sequence of digits and must repeat them in reverse order.	.63 (Reynolds, 1997)
Digit span forward (WAIS III)	(Wechsler, 1997)	The participant hears a sequence of numbers and then is asked to repeat them in the same order.	.89 (Matarazzo & Herman, 1984)
Digit symbol coding (WAIS- R)	(Wechsler, 1981)	A page headed by a key that pairs the single digits 1–9 with nine symbols is shown; the task consists of writing or orally reporting the correct number in the spaces below the symbols.	. 64 (Joy, Fein, Kaplan, & Freeman, 2000)

Forward memory span (CBTT)	(Milner, 1971)	In the computerized versions of these tasks, circles flash on the screen and caregivers reproduce the sequences by clicking on the circles. The subtest concludes when 2 consecutive errors on 1 sequence length are made.	.75 (de Paula, Malloy-Diniz, & Romano-Silva, 2016)
Free and cued selective reminding test	(Grober, Buschke, Crystal, Bang, & Dresner, 1988)	Sixteen pictures are presented in four sets of four on successive cards. Participants initially identified each item pictured to control for encoding, the card is then removed and immediate cued recall of the four items is tested. A brief numerical interference task was carried out before delayed free recall was assessed across three trials.	.85 (Ellen Grober, Ocepek-Welikson, & Teresi, 2009)
Mini Mental State Examination	(Folstein et al., 1975)	A widely used test of cognitive function among the elderly; it includes tests of orientation, attention, memory, language and visual-spatial skills.	.82 (Folstein et al., 1975)
Modified telephone interview for cognitive status	(Welsh, Breitner, & Magruder-Habib, 1993)	Cognitive domains measured by the TICS include orientation, concentration, short-term memory, language, praxis, and mathematical skills.	.99 (Monteiro et al., 1998)
Montreal cognitive assessment	(Nasreddine et al., 2005)	Designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation.	.96 (Luis, Keegan, & Mullan, 2009)
Number series task (WJ III)	(Woodcock et al., 2005)	Participant is required to identify and apply an analogue or rule to complete a numerical sequence. The mental representations (or "number sense") that constitute this ability form the basis for the ability to learn.	.8 (Grizzle & Davis, 2011)
Reverse memory span (CBTT)	(Milner, 1971)	Circles flash on the screen and caregivers reproduce the sequences in reverse order by clicking on the circles.	.78 (de Paula et al., 2016)
Story paradigm	(Palma et al., 2011)	Participants were exposed to an emotionally neutral story, or a closely matched but more emotionally arousing story. Participants were required to answer multiple choice questions on the story 24 hours later.	(Quevedo et al., 2003)
Stroop colour word test	(Houx et al., 1993)	Read words and colour naming in congruent and incongruent conditions.	.77 (Hedge, Powell, & Sumner, 2018)
Trail making A	(Army Individual	Requires the participant to draw lines on a page connecting 25 numbers consecutively as	.94

	Test Battery., 1944)	quickly as possible.	(Strauss et al., 2006)
Trail making B	(Army Individual Test Battery., 1944)	The participant must draw lines alternating between numbers and letters in consecutive order.	.94 (Strauss et al., 2006)
Vocabulary subtest (SILS)	(Zachary, 1986)	Recognition of verbal knowledge and includes 40 multiple-choice items. For each item the respondent must chose which 1 of 4 words is closest in meaning to a target work (i.e. synonym).	.87 (Lezak et al., 2012)
Wechsler Memory Scale-III	(Wechsler, 1997)	Logical Memory I and II test immediate and 30 minute delayed recall of short stories. For Letter Number Sequencing participants listened to a list of randomised numbers and letters of increasing lengths (from 2 to 8) and recited the numbers and letters from the lowest in each series, starting with the numbers. The span increased until the participant failed all three items of one length.	.82 (Lezak et al., 2012)
Word definition (WAIS-R)	(Wechsler, 1981)	Words are listed in the order of difficulty. The participant is required to explain what each word means.	.92 (Ryan, Arb, & Ament, 2000)
Word list recall test (CEDRAD)	(Moms et al., 1989)	It consisted of 3 immediate recall trials of 10 words presented visually and read by the participants. The delayed recall trial was conducted 10 minutes following the last immediate trial and was used for the primary analysis.	(Lezak et al., 2012)

Appendix D

Journal author guidelines – Systematic Review

All manuscripts submitted to *The Gerontologist* should address practice and/or policy implications.

*The word limits listed below include abstract, text, and references.

- Tables and figures are limited to 5 Word pages for all submission types except for Review Articles, for which 10 pages are allowed.
- To manage the word and page counts, authors are encouraged to submit detailed methodology, tables, and/or figures as supplementary material. If your manuscript is accepted, supplementary material is available to readers online only.

c. **Review Articles.** *The Gerontologist* welcomes submissions of state-of-the-art Review Articles (e.g. systematic/scoping reviews, umbrella reviews) and/or in-depth synthesis methodology reviews (e.g. meta-analyses). Manuscripts should be limited to 8,000* words. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement (PRISMA) flow diagram and checklist should be included in the submission (PRISMA checklist and flow diagram are available here). Note: Include the checklist as supplementary material only. It is permissible to add a column or space to the checklist that specifies where in the manuscript each component has been followed. y.

FORMATTING

Manuscripts are to be submitted in Microsoft Word or a Word-compatible program at ScholarOne. Manuscripts submitted in other formats will be unsubmitted and returned to the corresponding author for correction prior to editor review. Please DO NOT submit PDF versions of your manuscript submission materials. A peer-review title page will be created by the system and will be combined with the main document file into a single PDF document. This document will be used for the peer review

process. Each table should be editable and **in Microsoft Word or a Word-compatible program on a separate page at the end of the main document.**

The Gerontologist uses **APA style**. General guidelines follow; for more detailed information, consult the *Publication Manual of the American Psychological Association* (6th ed.).

Abbreviations: Ensure that the use of abbreviations is clear and that each one is defined in the text at its first mention only.

In-text References and Citations. Refer to the *Publication Manual of the American Psychological Association* (6th ed.) for style and see the FORMATTING section above. References in text are shown by citing in parentheses the author's surname and the year of publication. Example: ". . . a recent study (Jones, 1987) has shown. . . ." If a reference has two authors, the citation includes the surnames of both authors each time the citation appears in the text. When a reference has more than two authors and fewer than six authors, cite all authors the first time the reference occurs. In subsequent citations, and for all citations having six or more authors, include only the surname of the first author followed by "et al." Multiple references cited at the same point in the text are in alphabetical order by author's surname.

Instructions for Anonymous Files. Upload one anonymous version of your manuscript with no author names or contact information on the title page, blinded funding and/or acknowledgment details, and removed other self-identifying author information. Be sure to check there are no self-references in the text itself that would reveal the identity of the authors. Please remove those instances and insert the term "Blinded for Review" in its place. This includes self-references to your name(s) and University/Institute. This version may be seen by peer-reviewers.

Instructions for Non-Anonymous Files. Upload a complete version of the manuscript with all of the author and acknowledgment details. This version will be seen by the editors and will be the version published, IF accepted.

COMPONENTS OF THE MANUSCRIPT

Cover Letter (Optional). A cover letter is not required and is optional. It should explain how the manuscript is innovative, provocative, timely, and of interest to a broad audience, and other information authors wish to share with editors. Note: The cover letter for manuscripts will NOT be shared with reviewers.

Title page. A title page should be a completely separate page that includes the following:

(1) Title of the manuscript, APA recommends that a title be no more than 12 words. Although we recognize that 12 words may be too restrictive for some papers, please try to be concise in your title.

(2) **All** authors' full name(s) with academic degree(s), affiliations, and email addresses.

(3) The corresponding author should be clearly designated.

Abstract and Keywords. On a separate page, each manuscript must include a brief abstract. Structured abstracts for Research Articles, Brief Reports, and Intervention Research, Review Articles, and Measurement Articles submissions should be approximately 250 words (the web-based system will not accept an abstract of more than 250 words), and must include the following headings: **Background and Objectives, Research Design and Methods, Results, and Discussion and Implications.** Forum manuscripts must also include an abstract of about 200 words, but may be without structured headings.

Below the abstract, authors should supply three to five keywords that are NOT in the title. Please avoid elders, older adults, or other words that would apply to all manuscripts submitted to *The Gerontologist*. Note: Three keywords must be entered to move forward in the online submission process.

Text. The text of Research Articles, Brief Reports, and Intervention Research, Review Articles, and Measurement Articles submissions should follow the headings included in the structured abstract (see above Abstract and Keywords). Forum manuscripts should also be divided into headings, as appropriate for the submission. Articles may need subheadings within some sections to clarify their content. The Implications should not merely restate the results but should interpret the results and specify the policy and/or practice implications.

(1) The word counts for the different types of publications considered by the Journal are presented above and are inclusive of the abstract, text, and references.

(2) If manuscripts greatly exceed these word count limits, your manuscript may be returned to you for correction BEFORE the peer review process can begin. If you would like to appeal the word count limit for the text of the manuscript, permission must be granted by the Editor in Chief prior to submission. When submitting, please indicate in your cover letter that permission has been granted.

Acknowledgment (Optional). If the authors choose to include acknowledgments recognizing funders or other individuals, they should be placed on a separate page immediately following the title page. The self-identifying acknowledgments should be removed from the anonymous version of the manuscript.

Conflict of Interest. At the point of submission, each author should reveal any financial interests or connections, direct or indirect, or other situations that might raise the question of bias in the work reported or the conclusions, implications, or opinions stated - including pertinent commercial or other sources of funding for the individual author(s) or for the associated department(s) or organization(s), personal relationships, or direct academic competition. When considering whether you should declare a conflicting interest or connection please consider the conflict of interest test: Is there any arrangement that would embarrass you or any of your co-authors if it was to emerge after publication and you had not declared it?

As part of the online submission process, corresponding authors are required to confirm whether they or their co-authors have any conflicts of interest to declare, and to provide details of these. It is the corresponding author's responsibility to ensure that all authors adhere to this policy. If there is no conflict of interest, please include the statement: "We have no conflict of interest to declare."

Funding. Details of all funding sources for the work in question should be given in a separate section labeled "Funding." This should appear before the Acknowledgements section.

The following rules should be followed:

• The sentence should begin: "This work was supported by ..."

• The full official funding agency name should be given, i.e. "National Institutes of Health," not "NIH" (full RIN-approved list of UK funding agencies) Grant numbers should be given in brackets as follows: "[grant number xxxx]"

• Multiple grant numbers should be separated by a comma as follows: "[grant numbers xxxx, yyyy]"

• Agencies should be separated by a semi-colon (plus "and" before the last funding agency)

• Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number "to [author initials]."

An example is given here: "This work was supported by the National Institutes of Health [AA123456 to C.S., BB765432 to M.H.]; and the Alcohol & Education Research Council [hfygr667789]."

Oxford Journals will deposit all NIH-funded articles in PubMed Central. See http://www.oxfordjournals.org/for_authors/repositories.html for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above.

Crossref Funding Data Registry

To meet their funding requirements authors are required to name their funding sources, or state if there are none, during the submission process. For further information on this process or to find out more about the CHORUS initiative please click here.

Reference List. Arrange alphabetically by author's surname; do not number. The reference list includes only references cited in the text. Do not include references to private communications or submitted work. Consult the *Publication Manual of the American Psychological Association* (6th ed.) for correct form.

Examples:

Journals: Kaskie, B., Imhof, S., Cavanaugh, J., & Culp, K. (2008). Civic engagement as a retirement role for aging Americans. *The Gerontologist*, 48, 368–377. doi:10.1093/geront/48.3.368

Books: Quadagno, J. S. (1982). Aging in early industrial societies. New York: Academic Press.

Tables. Tables are to be numbered consecutively with Arabic numbers and have a brief title for each. Place table footnotes immediately below the table, using superscript letters (a, b, c) as reference marks. Asterisks are used only for probability levels of tests of significance (*p<.05). Tables should be placed at the end of the anonymous and non-anonymous manuscripts, following the references.

Figures/Illustrations. Please include your figures at the end of the anonymous and non-anonymous Word processing file.The Journal reserves the right to reduce the size of illustrative material. Each figure should be at sufficient resolution (i.e., 300 dpi at 5 in.) to be clear, sharp images when reduced to print size. Figures must be

professionally lettered in a Sans-Serif type (e.g., Arial or Helvetica). All labels used in figures should be in upper case in both the figure and the caption.

Color figures

Figures may appear in color online, but will only appear in color in print when deemed necessary. Please contact the editorial office for further information about color figures at tg@geron.org.

Captions for Tables and Illustrations

Type table titles and figure captions on a separate page following the references in the main document with numbers corresponding to the tables and illustrations. Table titles and figure captions should provide sufficient information so that the reader can understand the tables and figures with minimal reference to the text. Explain symbols, arrows, numbers, or letters used in illustrations. Explain internal scale and identify staining method in photomicrographs.

Appendices

All appendices will be published online only as supplementary material (please see FORMATTING and SUPPLEMENTARY MATERIAL instructions above).

Appendix E.

Journal Author Guidelines – Empirical

Author guidelines were copied and pasted from the journal website. See below.

Preparing Your Paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

Original article

- Should be written with the following elements in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list)

- Should be no more than 5000 words, inclusive of figure captions, footnotes, endnotes, excluding references, cover pages and tables/figures.
- Should contain a structured abstract of 250 words. A structured abstract should cover (in the following order): : Objectives, Method, Results, and Conclusion. Read tips on writing your abstract.
- Between 3 and 5 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

Appendix F

Ethics Approval

ER44 **ISSUES ARISING FROM THE PROPOSAL**

I can confirm that the above application has been reviewed by two independent reviewers. It is their opinion that:

a) Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary,

OR

b) The ethical issues listed below arise or require clarification:

It is an interesting and important research proposal.There is controversy around the use of appropriate language in dementia. The researcher is using 'perceived suffering' and this is not a person-centred care concept. See Dementia Action Alliance and the Living fully with Dementia: Words matter white paper. It has a good description of words to avoid and the rationale for doing it. Alzheimer's Society UK and Alzheimer's Scotland have also written documents with regards to the word 'suffering' in dementia.

1. Inclusion/Exclusion criteria, clarify if caring for a person with dementia in early, moderate or severe stages? And what type of dementia?; reword the item 'able to read, write and understand English' –
2. (ER11) It is concerning if the researcher will rely only on her personal lap top to store data, storage of data should be in line with University of Edinburgh guidelines.
3. Please remove the 'perceived suffering' title, as it is not in line with policy and person-centred guidelines in dementia care.
4. Participant Information Sheet and Consent for should comply with the GDPR guidelines for research provided by the University (see https://www.ed.ac.uk/files/atoms/files/researchgdpr_0.pdf)
5. Contact details: researcher should use her University's email and not a personal email.
6. Add the support resources and available services in case of feeling distressed.

The applicant should respond to these comments in section 8 below.

Signature:

Position: Chair SREC

Date: 05.10.18

1. Inclusion/Exclusion criteria, clarify if caring for a person with dementia in early, moderate or severe stages? And what type of dementia?; reword the item 'able to read, write and understand English' –	**Page 6 & 17** Added to INCLUSION criteria, highlighted in BLUE • "providing carer to the care recipient in the home environment • providing care for a minimum of 4 hours per day • caring for a person with the following types of dementia; Alzheimer's disease, Vascular dementia, Dementia with Lewy bodies, Frontotemporal dementia • can understand written English EXCLUSION • caring for a person with dementia as a result of: posterior cortical atrophy, Creutzfeldt-Jakob disease, down syndrome and dementia, Huntington's disease, Parkinson's disease dementia, normal pressure hydrocephalus and Korsakoff syndrome, mixed dementia **Page 5** Clarification re stage of dementia with be gathered using demographic information. All stages of dementia will be included in study
2. (ER11) It is concerning if the researcher will rely only on her personal lap top to store data, storage of data should be in line with University of Edinburgh guidelines.	**Page 7** "A master copy of the digital data will be stored on the University of Edinburgh password protected network drive, known as DataStore. DataStore provides fully backed up, secure and multisite storage for researchers, allowing them to access via Virtual Private Network (VPN) from outside of the University. This will ensure the data is stored in a single place and backed up regularly, ensuring security, minimising risk of loss, theft or unauthorised use."

ER45 **APPLICANT'S RESPONSE (If required)**

4. Participant Information Sheet and Consent for should comply with the GDPR guidelines for research provided by the University (see https://www.ed.ac.uk/files/atoms/files/researchgdpr_0.pdf)	**Appendix 1,2,3,** I have now very closely followed template provided to ensure they comply with regulations. Where participants complete the survey online, they will not be able to provide signature. However, it will not be possible for them to proceed, without them ticking the consent box.
5. Contact details: researcher should use her University's email and not a personal email.	Amended to use university email address in A1 and A4
6. Add the support resources and available services in case of feeling distressed.	**Appendix** 4 List of Mental health charities, reference to GP

Signature:

Date: 19/11/18

ER46 **CONCLUSION TO ETHICAL REVIEW (if required)**
The applicant's response to our request for further clarification or amendments has now satisfied the requirements for ethical practice and the application has therefore been approved. Signature: Ethel Quayle Position: Chair SREC Date: 10.12.18
ER47 **AMENDMENT/S: REQUEST FOR APPROVAL**

Appendix G

List of Support Forums

The following support groups were accessed via social media. The survey was posted with permission from the administrator.

Dementia Caregivers Support Group

Dementia and Alzheimer's UK Carers Group

Dementia Aware

Support for Vascular, Alzheimers and Mixed Dementia

The Unforgettable Dementia Support Group

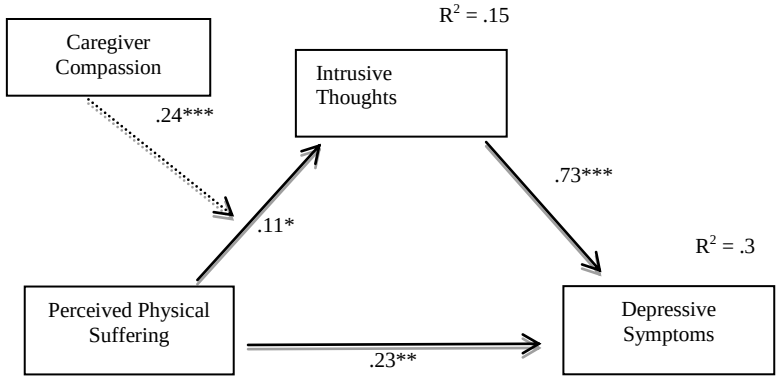
Dementia Carer Voices

Support for Vascular, Alzheimer's & Other Dementia

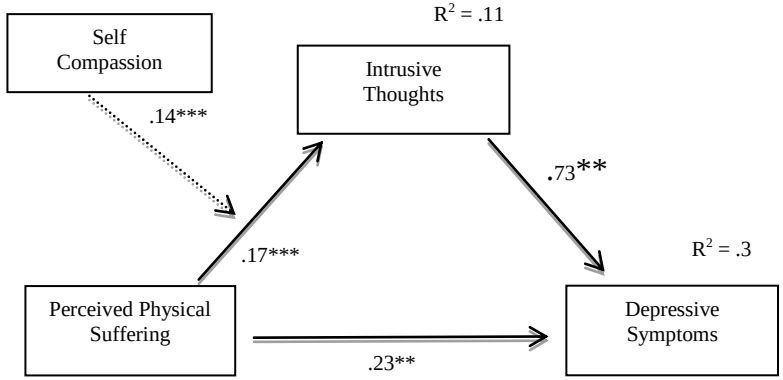
Dementia carers support g

Appendix H. *Summary of Models*

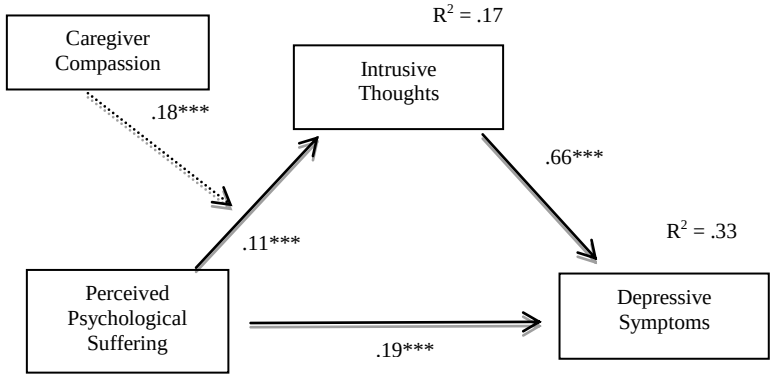
Model 1.



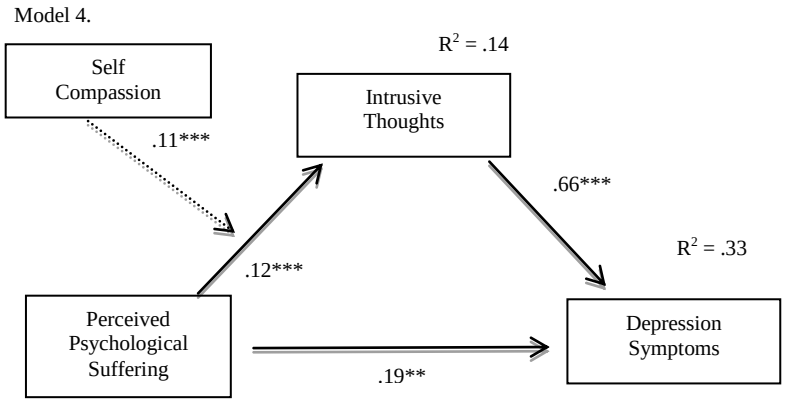
Model 2.



Model 3.



Model 4.



Note. Number on the paths represents standardised b coefficients * p <.05 **p <.01 **p<.001. Only significant paths are shown.

Appendix I

Research Proposal

Doctorate in Clinical Psychology

Thesis Research Proposal
(For Methodological Review Only)

This form is for methodological review of projects that are **not** being submitted as assessed work for Research 1. (e.g. where a trainee has already received a pass mark for Research 1, but subsequently changed the intended thesis project, or for trainees who started training in 2009 or earlier and thus did not need to complete Research 1 and have not previously had university approval for their study).

In such circumstances the form will be reviewed by a member of the academic team and will receive detailed feedback, but will not be graded. The feedback will include an evaluation of the viability of the project and any recommendations. If there are significant concerns about viability, the project will be flagged to the research director and the research committee will decide whether the project can proceed in its current form.

Trainee Name

Jenni Adams

Provisional Thesis Title
Perceived suffering, intrusive thoughts and psychological wellbeing: an exploration of the role of self and other compassion in dementia caregivers

Proposed Setting
Third Sector

Allocated Thesis Project Supervisors	
Clinical	Lesley Walker/ April Quigley
Academic 1	Karen Goodall
Academic 2	
Others Involved	

Anticipated Month / Year of Submission Must be May of final year. Trainees from 2011 intake onwards must submit in May. Trainees who started in 2010 or earlier are advised to submit in May to reduce potential for HCPC registration difficulties.
March 2020

Date Form Submitted / Version
28/09/18

Please Note: Whilst this is not an ethics review process, where questions have some similarities to questions contained in the NHS IRAS Research Ethics form, the corresponding IRAS question numbers are given in parentheses. This is intended to facilitate completion of NHS ethics where such approval is needed.

Section 1: Introduction

1.1 Provide a brief critical review of relevant literature, which should clearly demonstrate the rationale and scientific justification for the research

1306 words

Relevant to IRAS A12

Caregiving

The chronic strain of caregiving often results in increased levels of stress, social isolation and emotional or physical health deterioration (Ory et al., 1999). As such, current policy outlined by the National Health and Wellbeing Outcomes (NHWO; Scottish Government, 2015, p.5) aims to ensure "people who provide unpaid care are supported… to reduce any negative impact of their caring role on their health and wellbeing". Estimates suggest around 850,000 people currently live with dementia in the UK (Prince et al., 2014), and that two thirds of these individuals are cared for in the home environment (Department of Health, 2009). Caregiving for someone with dementia presents serious cognitive, emotional, relational, and role challenges to family caregivers (e.g., Savla et al., 2011), and confers psychological and physical health risks, including higher risks of both psychiatric morbidity and mortality (Capistrant et al., 2012; Joling et al., 2010; Klein et al., 2014; Perkins et al., 2013).

A meta-analysis (Pinquart & Sorensen, 2003) found carers of people with dementia were significantly more stressed than carers of people who did not have dementia. More specifically, the researchers found dementia caregivers exhibited greater depressive symptoms, as well as suffered from more physical health problems. The prevalence of depression in dementia caregivers is extremely high, ranging between 22-70% (Givens et al., 2014; Bednarek et al., 2016; Omranifard et al., 2018), whilst studies suggest the prevalence of anxiety is around 44% (Sallim et al., 2015).

Perceived physical suffering and intrusive thoughts

A recent paper illustrated the significance of thought reactivity when exploring depression in dementia caregivers (Schulz et al., 2017). In an attempt to improve understanding regarding dementia caregiver's psychological wellbeing, the researchers explored the role of perceived suffering in the care recipient (CR) and intrusive thoughts in caregiver depression (Schulz et al., 2017). Findings illustrated caregiver's perception of the CR physical suffering led to an increase in caregiver depression, suggesting that appraisals of the CR suffering can have harmful effects on caregivers. Furthermore, the researchers found that intrusive thoughts mediated this relationship, demonstrating that the occurrence of unwanted thoughts and intrusions is integral to caregiver wellbeing.

These findings may help to explain the success of mindfulness-based interventions, which have been found to have a positive impact on dementia caregiver's psychological wellbeing (Hou et al., 2013; Oken et al., 2010; Whitebird et al., 2013, Brown et al., 2016). Mindfulness strategies actively encourage individuals to attend to thoughts, as opposed to try and suppress them, and attending to thoughts has been found to reduce the experience of intrusions, whilst suppression can unintentionally heighten intrusions (Abramowitz et al., 2001). If caregivers were to experiences fewer intrusions, it would be expected that psychological wellbeing would improve, since evidence suggests intrusive thoughts play a cause role in the development and maintenance of negative emotions (Lepore, 1997).

Compassion

Recent findings among dementia caregivers have also suggested that compassion moderates the relationship between perceived physical suffering and intrusive thoughts (Schulz et al., 2017), suggesting compassion is a risk factor for negative caregiver outcomes. These findings contradict expectations, since most mindfulness-based interventions teach elements of compassion (Grossman et al., 2004) and there is a body of evidence that highlight the benefits of compassion (Neff at al., 2007; Neff & McGehee, 2010). This suggests that a greater understanding of the relationship between compassion, intrusive thoughts and psychological wellbeing among dementia caregivers is needed.

Self-compassion and other compassion are two related constructs that are often studied separately. Recent findings suggest self-compassion and other compassion are not significantly related (Lopez, 2017), however Schulz et al. (2017) did not consider their differential roles in their research. Close examination of Schulz et al 's (2017) outcome measure for compassion appears to focus on questions related to other compassion, which would suggest the findings should report other compassion (and not self compassion) strengthens the relationship between perceived physical suffering and intrusive thoughts. These findings make intuitive sense, since compassion for others could increase worry and concern, leading to

rumination and intrusions about an individual's well being.

In light of the limitations highlighted above, further research is needed to clarify if individuals who score high on other compassion, demonstrate poorer psychological wellbeing, in comparison to those who score high on self-compassion.

Self compassion

Self-compassion is considered an adaptive method of relating to oneself and one's experience following exposure to difficulties and adverse experiences (Barnard and Curry 2011; Neff and McGehee, 2010). According to a systematic review, high self-compassion is associated with reduced stress, anxiety, and depressive symptoms (MacBeth & Gumley 2012) and as such, establishing a self compassionate perspective may help buffer against the negative effects of caring for an individual with dementia. Whilst these findings provide clear evidence for the benefits of self-compassion, evidence regarding other compassion is under researched.

Other compassion

Other-compassionate interventions have been found to have both immediate and long-term psychological health benefits, including mood state (Millar et al., 1988), reduced depressive symptoms (Krause et al. 1992; Taylor and Turner 2001), and increased self-esteem (Krause and Shaw 2000). In addition, other compassion has been found to increase individuals' positive affect (Klimecki et al. 2012); self reported happiness (Mongrain et al., 2011) and decrease negative affect (Stuntzner, 2014). The above studies suggests that other compassion is generally associated with greater wellbeing, however evidence from Schulz et al. (2017) provides preliminary evidence that this hypothesis is not supported in the context of caring for an individual with dementia. Schulz et al. (2017) found that other compassion is in fact a risk factor for depression in caregivers of dementia, increasing the experiences of intrusive thoughts about the CR, leading to symptoms of depression. In light of this, further research is needed to validate the conclusions drawn by Schulz et al. (2017), and extend the findings beyond depression. Understanding these findings could have significant implications for dementia caregivers, informing and shaping current and future therapeutic interventions, which aim to reduce the negative impact of caregiving.

Rationale

Evidence suggests that compassion for self and others are protective traits that should be cultivated in order to benefit psychological wellbeing. Recent findings from Schulz et al. (2017) questions the validity of these findings in dementia caregivers, highlighting that other compassion may in fact be a risk factor for caregiver depression. Further research is needed to improve understand of these

findings, and explore the relationships between perceived suffering, intrusive thoughts, compassion and psychological wellbeing. Based on the above literature, it is hypothesised that:

H1 Perceived suffering of the person with dementia will predict psychological wellbeing (depression/anxiety outcomes) in the caregiver

H2 The relationship between perceived suffering and psychological wellbeing will be mediated by intrusive thoughts

H3 The mediating effects of intrusions will be moderated by compassion. It is expected that self-compassion will reduce the mediating effects of intrusive thoughts and other compassion will increase the mediating effects of intrusive thoughts

If the above hypotheses are accepted, target interventions could focus on increasing a sense of self-compassion in dementia caregivers and reducing qualities in other compassion. Psycho education may be used to educate individuals regarding the need for self-compassion and kindness, as well as highlight the risks of other compassion. Strategies could be developed to enable caregivers to attend to unpleasant thoughts around the CR's suffering (such as mindfulness based interventions), which could help to reduce the frequency of intrusive thoughts and therefore promote psychological wellbeing.

If the above hypothesis are not supported, and other compassions is found to reduce the mediating effects of perceived suffering and intrusive thoughts, current interventions which employ other compassion could be more confidently implemented across different contexts. If other compassion is not perceived as a risk factor for caregivers, other compassion should be cultivated, in order to promote high quality caregiving for the CR. By its very nature, other compassion would motivate caregivers to reduce suffering as much as possible and respond with empathy and kindness.

Section 2: Research Questions / Objectives

2.1 What is the principal research question / objective?

IRAS A10

What roles do self and other compassion play in the relationship between

perceived suffering, intrusive thoughts and caregiver wellbeing?

2.2 What are the secondary research questions / objectives, if applicable?

Keep these focused and concise, with a maximum of 5 research questions

IRAS A11

In dementia caregivers:

1. Do intrusive thoughts mediate the relationship between perceived suffering and psychological wellbeing (depression/anxiety)
2. Does self-compassion moderate the mediation effect of intrusive thoughts on the relationship between perceived suffering and psychological wellbeing?
3. Do other compassion moderate the mediation effect of intrusive thoughts on the relationship between perceived suffering and psychological wellbeing

Section 3: Methodology

3.1 Give a full summary of your design and methodology

It should be clear exactly what will happen at each stage of the project

IRAS A13

Design

The research study will use a cross-sectional, quantitative, within-groups design. Participants will be invited to complete a series of five self-report measures, exploring perceived physical suffering, self-compassion, other compassion, intrusive thoughts and psychological wellbeing.

Procedure

Adults over the age of 18 caring for an individual with dementia will be recruited from the general population. Recruitment will include participants sought from online sources, third sector support and charitable groups (Alzheimer Scotland, Dementia Café events, For Get Me Notes Signing group etc.). Leaflets and posters will be used to advertise the study in the community and online. The information on the posters will advertise the purpose of the study and invite participants to take part. Participants will be directed to the online questionnaire using a web link,

or will complete the study in person using paper copies of the questionnaire. The full aims and timings of the study will be outlined on an information sheet before participants provide consent to take part. Participants will be made aware that they can discontinue at any time.

Basic demographic information regarding age, gender, number of months/years spent caring, time spent caring each day, education level and relationship to the individual with dementia will be collected. Participants will be asked to complete 6 standardised self-report measures, including the *Experience of Suffering Scale (Schulz et al., 2010), Caregiver Compassion Scale (CCS,* Feeny & Collins, 2001; 2003*)*, *The Self Compassion Scale –Short form (SCS, Raes et al., 2011*), an adapted version of *The Impact of events scale (IES; Horowitz et al., 1979; Schulz et al., 2017)* and Hospital Anxiety and Depression Scale (HADS, *Zigmond & Snaith, 1983).* Upon completing the standardised measures, participants will be thanked for their participation, and will have the opportunity to provide contact details, should they wish for the researcher to contact them with the studies findings.

The data gathered will be pulled from online as well as the physical copies of questionnaires returned to the researcher. Raw data will be entered into SPSS and stored at the University of Edinburgh. The data will be analysed using SPSS and PROCESS. Finally, the data will be encrypted and held on a password protected memory stick.

3.2 List the principal inclusion and exclusion criteria

IRAS A17-1 and IRAS A17-2

Inclusion criteria

To be accepted for the research study, individuals will be:

- over age 18
- caring for a person with dementia
- English speaking
- able to read and write

Exclusion criteria

Individuals will be considered unsuitable for the research study if:

- they are paid caregivers, i.e. support staff, third sector agency staff
- the participant is unwilling or unable to provide consent

3.3 How will data be collected?

If quantitative, list proposed measures and justify the use of these measures. If qualitative, explain how data will be collected, giving reasonable detail (don't just say "by interviews".)

Demographic data

Data involving demographic information will be collected before the battery of measures is administered. The following self-report measures will be administered:

Experience of Suffering

The *Experience of Suffering Scale (ESS (Schulz et al., 2010))* was selected as this measure was used in the Schulz et al. (2017) study. The ESS can be broken down into two separate scales; physical suffering and psychological suffering.

Physical Suffering

The caregiver's perception of the CR's physical symptoms over the past week is rated on nine items. Each item is rated on a 4-point scale from 0 (Not at all) to 3 (Very often/Every day). The physical suffering score is computed by summing scores across all the items, with higher scores indicating higher perceived physical suffering. The ESS for physical symptoms has demonstrated good internal consistency (Cronbach's alpha = 0.64) (Schulz et al. 2010).

Psychological Suffering

The caregiver's perception of the CR's psychological symptoms over the past week is rated on 15 items. For each item, the caregiver is asked how often the CR has

experienced each of the 15 feelings during the past week, along the same 4-point rating scale. The psychological suffering score is computed by summing all 15 items, with higher scores indicating higher perceived psychological suffering. The ESS for psychological symptoms has demonstrated good internal consistency (Cronbach's alpha = 0.89) (Schulz et al. 2010).

Other Compassion

The Caregiver Compassion Scale (CGCS (Feeny & Collins, 2001; 2003)) was selected as this measure was used in the Schulz et al. (2017) study. The measure is specifically designed for measuring compassion in close personal relationships. The CGCS consists of 11 items asking caregivers the extent to which they agree or disagree with feelings of compassion towards the care CR (e.g. 'It is difficult for me to see my partner/relative suffer'; 'It is important for me to try to do everything possible to help reduce the suffering of my partner/relative'. Each item is rated on a 5-point scale from 1 (strongly agree) to 5 (strongly disagree). The CSC demonstrated good internal consistency in Schulz et al. research (Cronbach's alpha = 0.79).

Self Compassion

The *Self-Compassion Scale –Short form (SCS, Raes et al., 2011*) consists of 12 items asking individuals how they typically act towards their self in difficult times. Each item is rated on a 5-point scale from 1 (almost never) to 5 (almost always), allowing a total self-compassion score to be calculated. The SCS-SF has demonstrated good validly, reliability and internal consistency (Cronbach's alpha = 0.86), and has a near perfect correlation with the long form SCS (r=.96) (Raes et al., 2011).

Intrusive thoughts

An adapted version of the *Impact of events scale (IES; Schulz et al., 2017; Horowitz et al., 1979)* was selected as this measure was used in the Schulz et al. (2017)

study. The adapted IES includes seven items extracted from the IES, which focus on intrusion (as opposed to including elements of avoidance). The original IES (Horowitz et al., 1979) has been shown to have good internal consistency with alpha coefficients of .78 for the intrusion sub scale and .82 for the avoidance subscale (Horowitz et al., 1979), with an overall internal consistency of 0.86.

In the adapted IES individuals are asked to complete a seven items which assess the extent to which caregivers were unable to inhibit thoughts about the CR illness (e.g. 'I thought about the care recipient illness when I did not mean to'). Each item is rated from 0 (not at all) to 3 (often). A total score is provided, with higher scores indicating an inability to shutdown intrusive thoughts. Schulz et al. (2017) reported the adapted IES had good internal consistency (Cronbach's alpha =0.79.

Psychological Wellbeing

The *Hospital Anxiety and Depression Scale (*HADS, Zigmond and Snaith, 1983) consists of 14 items aimed at measuring of anxiety and depression. The HADS anxiety and depression subscales each consist of seven related items. Each item is rated on a four-point scale from 0 to 3, yielding a maximum score of 21 for each subscale. The HADS has been found to have good psychometric properties, with a Cronbach's alpha of 0.83 (Bjelland et al., 2002).

Section 4: Sample Size
4.1 What sample size is needed for the research and how did you determine this?

For quantitative projects, outline the relevant Power calculations and the rationale for assuming given effect sizes. For qualitative projects, outline your reasoning for assuming that this sample size will be sufficient to address the study's aims *IRAS A59 and IRAS A60*
The proposed sample size has been estimated based on the secondary research question "Do intrusive thoughts mediate the relationship between perceived physical suffering and psychological wellbeing?" Researchers, Fritz and MacKinnon (2007) have developed a guideline for which researchers can refer to when aiming to attain a 0.8 power to detect small, medium and large effect sizes when using simple mediation analysis. Fritz and MacKinnon (2007) suggest that to compute an accurate sample size, the effect sizes for the 'a' and 'b' pathways are extracted from previous research and used to inform the study in question. For the current research, the 'a' pathway in the mediation analysis is the relationship between perceived physical suffering and intrusive thoughts, whereas the 'b' pathway is the relationship between intrusive thoughts and psychological wellbeing. Schulz et al. (2017) explored the relationship between perceived physical suffering and intrusive thoughts, reporting a medium effect size. Schulz et al. (2017) explored the relationship between intrusive thoughts and depression, reporting medium effect size. Baider et al. (1997) explored the relationship between intrusive thoughts and psychological wellbeing, reporting a medium effect size. Based on the above findings, Fritz and MacKinnon (2007) suggest a sample size of 124.
4.2 Outline reasons for your confidence in being able to achieve a sample of at least this size Give details of size of known available sample(s), percentage of this type of sample

that typically participate in such studies, opinions of relevant individuals working in that area
A range of measures have been undertaken to encourage a sufficient number of participants take part in the study. Data will be collected from varying recruitment routes, providing ample opportunity to recruit a large and diverse sample. <u>Online</u> The primary researcher's current contact with online support pages has provided access to thousands of dementia caregivers. Current contact with support page members suggests the population at hand are interested and motivated to contribute to the current research. To ensure the sample size can be met, multiple support pages have been contacted, and chat rooms and message boards will also be targeted. The use of online support pages will allow the researcher to gain access to populations outside of the local area and allow data to be collected over a lengthy period of time, without the researcher having to be present. <u>Council and third sector</u> As many carers are often older adults, and only 41% of adults above the age of 75 use the internet (Office for National Statistics, 2017), the researcher will aim to contact older adults in person via third sector groups. The primary researcher has identified at least nine local support groups who will be contacted regarding the research study.

Section 5: Analysis
5.1 Describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative methods) by which the data will be evaluated to meet the study objectives *IRAS A62*
The PROCESS macro for SPSS will be used to examine the raw data using a regression based approach to mediation. **Demographics** T-tests will be used to compare demographic information and key variables. For example, individual t-tests will compare 'psychological wellbeing' and 'length of

time spent caring (more or less than five years)' to evaluate whether the groups differ. If non-parametric data is detected, Mann-Whitney, Spearman rho, or Kruskal-Wallis tests will be applied.

Mediation Analysis

It is hypothesised that intrusive thoughts will mediate the relationship between perceived physical suffering and psychological wellbeing in dementia caregivers. A simple mediation model will be employed to test this hypothesis, using 'perceived physical suffering' as the predictor variable (IV), intrusive thoughts as the 'mediator variable' and 'psychological wellbeing' as the outcome variable (DV). Indirect and direct effects will be computed and reported with 95% confidence interval, using a linear regression procedure. Effects will be deemed to be statistically significant if the upper and lower range do not go through zero.

A bias corrected bootstrap test of mediation will be applied, as endorsed by Preacher and Hayes. This is considered to be the most effective methodology when researching a small sample size. Bootstrapping attempts to protect data from Type 1 errors, does not assume normal distributions for any variable, and is a nonparametric resampling procedure.

Mediation analysis will be performed irrespective as to whether a correlation is detected between other compassion and psychological distress. This is because modern mediation analysis does not necessitate a relationship between the predictor variable and the outcome variable as a pre-requisite (Hayes, 2013). Should the researcher encounter difficulties regarding statistical analysis during the stage of data analysis, advice will be sought by consulting a statistician for their expertise.

Section 6: Project Management / Timetable

6.1 Outline a timetable for completion of key stages of the project

E.g. ethics submission, start and end of data collection, data analysis, completion of

systematic review

	Sept > Oct	Nov > Dec	Jan > Feb	Mar > Apr	May > Jun	Jul > Aug	Sept > Oct	Now > Dec	Jan > Feb	Mar > Apr	May > Jun	Mar > Apr
Submit proposal												
Submit ethics												
Research prep												
Systematic review												
Data collection												
CP2												
Data analysis												
Thesis write up												
Submit thesis												
Dissemination												
Viva												

Section 7: Management of Risks to Project

7.1 Summarise the main potential risks to your study, the perceived likelihood of occurrence of these risks and any steps you will or have taken to reduce these risks. Outline how you will respond to identified risks if they should occur

Risk	Likelihood	Measure to eliminate/minimise risk
The study will fail to gain ethical approval, delaying recruitment and data collection	Low	- The ethics application will be submitted at the earliest possible date (see GANTT chart) to allow time to resubmit form if necessary - Advice will be sought from the University of Edinburgh research team will be consulted to ensure the ethics application meets the appropriate level of detail before submission
The study is underpowered due to lack of participants	Medium	- A proactive stance to recruitment will be taken using a number of pathways (online, third sector, local council authorities) - Recruitment will begin at the earliest possible date, allowing for data to be collected over a 10-month period if necessary
Participation burden due to length and time taken to complete the study	Low	- The measures chosen were carefully selected with consideration regarding participation burden in mind - Participants will be aware of the completion time for the battery of measures
Participants may experience psychological distress when completing self-report measures due to emotions brought up around caregiving experience	Medium	- Before taking part in the study, individuals will be advised that the study may contain subject matter that individuals might find distressing - The debrief process will include details for additional support groups and helplines

Loss of data	Low	- All documents completed in paper form (as opposed to online) will be stored in a safe and confidential location at all times - Raw data will be collated on a spread sheet after data collection and will be backed up at regular intervals - Data gathered online will be checked and pulled to the master data set frequently - The master data set will be held in a highly secure base, on the University of Edinburgh Datastore

Section 8: Knowledge Exchange

8.1 How do you intend to report and disseminate the results of the study?

IRAS A51

Upon completion of the research analysis, the findings will be written up in the form of a doctoral thesis. The general public will have free access to the thesis which will be made available online via the Edinburgh Research Archives.

An article based on the studies findings will be provided for publication to a journal, such as *Aging and Mental Health.* Furthermore, the published article would be promoted using social media to ensure that the article is made accessible to the widest possible audience. As such, the article would be posted on support groups, Facebook, twitter, and any other relevant social media platform.

Additional opportunities to disseminate the research findings will be actively sought out. Relevant events to disseminate the research findings could involve departmental continued professional development sessions, as well as local poster sessions. Furthermore, a summary of findings could be submitted to "The Psychologist" and to the BPS Clinical Psychology forum, the gain wider access beyond local area. Finally, the results will be summarised and made accessible to participants of the study, subsequent to submission.

8.2 What are the anticipated benefits or implications of the project?

E.g. If this is an NHS project, in what way(s) is the project intended to benefit the NHS?

The current research hopes to contribute to psychological theory and inform professional practice. Working in line with the Dementia Pathway, the current research contributes to current NHS and government priorities, and hopes to contribute to the limited evidence base. As such, research findings could be used to develop, plan and provide the most effective treatment models and psychometric tests related to caregiving.

The research findings have the potential to inform new interventions which best support caregivers in the face of growing demands and economic burden. If other compassion serves as a risk or maintaining factor in the onset and course intrusive thoughts, and thus increase the likelihood of poor psychological wellbeing, then other compassion could represent promising therapeutic targets. The current research could therefore inform specific interventions that focus on optimizing self-compassion, promising to enhance long-term recovery and resilience.

Demographic data could highlight different experiences of caregiving depending on relationship to the CR, age or education. This information could be used to improve current understanding regarding the impact of caregiving, and allow for the development of tailored interventions that reach the entire network of caregivers. By developing more effective evidence-based interventions, the NHS and social care could hope to ease the economic burden of care giving by best supporting individuals to remain within the home environment.

8.3 Are the any potential costs for the project?

Outline any potential financial costs to the project, including the justification for the costs (why are these necessary for the research project?) and how funding will be obtained for these costs (how will they be met?) Please separate these into potential costs for the University and potential costs for your NHS Board and note that you should ask your NHS Board to meet stationery, printing, postage and travel costs.

The costs outlined are expected to be minimal, due to the study partially being completed online.

NHS Board

The NHS Board will cover the costs outlined below:

- printing of posters leaflets for the advertisement and recruitment of the study
- printing of self report measures, all of which are freely available for use
- printing of any additional documents needed to conduct the research (such as consent forms)
- printing of research poster required for presenting
- stationery (e.g. notebooks, pens etc.)

Section 9: Any Other Relevant Information

Section 10: Key References

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Section 11: Confirmation of Supervisors' Approval	
"I confirm that both my Academic and Clinical Supervisors have seen and approved this research proposal and have both completed the supervisors' appraisal forms below." *Delete as appropriate*	
Yes	No

Appendix 1

Main Academic Supervisor's Appraisal of Project Risk

Supervisor's Name
Karen Goodall

Date
28/09/18

Do you consider that the project should proceed in broadly its current form? *Delete as appropriate*		
Yes x	Yes, subject to the revisions outlined below	No

Outline the reasons for the above response Highlight any areas of risk to the completion of the project that have not been fully addressed within the proposal and any steps that could be taken to reduce risks

Appendix 2

Clinical Thesis Supervisor's Appraisal of Project Risk

Supervisor's Name
Dr April Quigley

Position
Consultant Clinical Psychologist Older Adult Psychology – Head of Specialty

Date
02-10-18

Do you consider that the project should proceed in broadly its current form? *Delete as appropriate*		
Yes		

Outline the reasons for the above response Highlight any areas of risk to the completion of the project that have not been fully addressed within the proposal and any steps that could be taken to reduce risks